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Leprosy epidemiological trends and diagnosis delay in three districts of Tanzania: A baseline study

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Summary

Objectives Leprosy, also known as Hansen's disease, is a slowly progressive and chronic infectious neglected tropical disease (NTD) caused by *Mycobacterium leprae*. This study was performed to assess the epidemiological trend of leprosy in the past five years in the three study districts in Tanzania in which a leprosy prevention intervention study (PEP4LEP) is implemented, and to determine the case detection delay at baseline.

Methods Secondary data from the leprosy registry of the National Tuberculosis and Leprosy Program of Tanzania from 2015 to 2019 were used to describe the epidemiological trends of leprosy for the three study districts: Morogoro, Mvomero, and Lindi district council. A cross-sectional study was also conducted to assess the delay in leprosy diagnosis at baseline. The chi-square test was used to calculate statistical significance.

Results Between 2015 and 2019, 657 new leprosy cases were detected in three districts. Of those cases, 247 (37.6%) were female patients, 5 (0.8%) had a grade 2 disability (G2D) and 516 (78.5%) had multibacillary (MB) leprosy. From the 50 adult leprosy patients interviewed for detection delay, 16 (32.0%) were females and 38 (76.0%) had MB leprosy. Overall, a mean case detection of 28.1 months (95% CI 21.5–34.7) and a median of 21.5 months were observed.

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Conclusion The three PEP4LEP study districts remain highly endemic, with long case detection delays observed that increase the risk of disabilities and contribute to ongoing leprosy transmission. Integrating activities such as contact screening and provision of post-exposure prophylaxis are therefore a necessary strategy in these endemic areas.

Keywords: Leprosy, epidemiology, case detection delay, Tanzania

Introduction

Leprosy is a curable infectious disease caused by *Mycobacterium leprae (M. leprae)*.[1,2] It has been a major global health problem for many centuries.[3] Leprosy predominantly affects the skin, nerves and eyes and causes a diverse disease presentation depending on the host's immune response and the bacillary load.[4] The introduction of multidrug therapy (MDT) in 1981 was necessary due to a reported increase of dapsone drug resistance and to shorten the treatment duration, which resulted in a marked reduction of leprosy patients on treatment.[5] MDT is freely available for the treatment of all patients with leprosy as part of the strategy of combating the disease and reducing its prevalence to less than one case per 10,000 population. This contributed to a reduction of the current new case detection of around 200,000 worldwide annually, but this global incidence level has been relatively stable in the past years.[2,6]

Different strategies which aim to further reduce the leprosy burden are in place in most endemic countries. A relatively new strategy is contact tracing combined with the administration of single dose rifampicin as post-exposure prophylaxis (SDR-PEP) to contacts of leprosy patients to reduce the risk of developing leprosy and the further transmission of *M. leprae*.[6] In 2018, the World Health Organization (WHO) included a recommendation to implement SDR-PEP in national leprosy programs in their "Guidelines for the Diagnosis, Treatment and Prevention of Leprosy".[7]

The PEP4LEP study is a cluster-randomised implementation trial comparing two interventions of integrated skin-screening combined with SDR-PEP distribution to contacts of leprosy patients in Ethiopia, Mozambique, and Tanzania.[8] In Tanzania, the project is implemented in three districts: Morogoro which has a population of 286,248, Mvomero with 312,109 and Lindi rural, which has a population of 194,143 according to National Bureau of Statistics Tanzania website as per 2012 census.[9]

Tanzania is among the 23 WHO global leprosy priority countries that combined contributed to 95.8% of new cases of leprosy globally in 2019.[4] According to the National Tuberculosis and Leprosy Program (NTLP) annual reports, Tanzania recorded a total of 7714 new leprosy cases in Morogoro and Lindi from 2015 to 2018.[10–13] It is pertinent to know the epidemiological trends in the three districts that implement the PEP4LEP project before the start of the project, to better analyze the impact of the project at the end of the implementation.

Key components of the leprosy control programs are the facilitation of early diagnosis through the recognition of changes of the skin and prompt anti-leprosy treatment for patients.[14] It is necessary to detect this disease in an early stage to prevent physical, psychological and social consequences.[15] Delays in diagnosis increase leprosy morbidity and the risk of disabilities. In 2010, 5.8% of all newly diagnosed leprosy cases globally had grade 2 disability (G2D) at the time of diagnosis.[16] Several factors contribute to the delay of leprosy diagnosis: the long incubation period of leprosy which typically ranges from 2 to 12 years and sometimes up to 20 years;[17] reduced awareness regarding early signs of leprosy, particularly

in low endemic areas, among patients and health workers; cultural beliefs and practices relating to the disease; patient health-seeking behavior, which is highly determined by their level of knowledge; socioeconomic constraints; fear of stigmatization; lack of knowledge on e.g. the disease's etiology and treatment options; the distance to health clinics and skills regarding leprosy among healthcare providers, particularly in areas where leprosy has been well controlled and new patients are not frequently seen.[18–20]

The aims of this Tanzanian PEP4LEP baseline study were: (1) to describe the epidemiological trends of leprosy over five years in the three districts of Tanzania in which the PEP4LEP project will be implemented and (2) to estimate case detection delay for diagnosis of leprosy cases at PEP4LEP baseline.

Material and methods

STUDY DESIGN AND LOCATION

Two approaches were used: a retrospective analysis for aim one, and a cross-sectional approach for aim two. For the retrospective analysis, the leprosy trends between 2015 and 2019 from the three districts in Tanzania where the PEP4LEP project will be conducted were reviewed and analyzed. The data was obtained from the NTLP database that records leprosy information from all 132 districts and 25 regions of the Tanzania mainland.

The diagnosis of leprosy patients is based on clinical signs, using the cardinal signs of leprosy, and according to WHO classification criteria, whereby paucibacillary (PB) is defined as five or fewer skin patches with loss of sensation, while multibacillary (MB) is defined as six or more skin patches with loss of sensation and/or an affected nerve.[7] A cross-sectional study was conducted between September 2019 and January 2020 in leprosy care centers located in two regions of Tanzania, Morogoro, and Mwanza, to determine the mean detection delay (Figure 1). New leprosy patients diagnosed between June and December 2019 were asked for consent to participate in the study.

STUDY SETTING: STRUCTURE AND FUNCTION OF THE (LEPROSY) HEALTH SYSTEM IN TANZANIA

The healthcare system in Tanzania has 7819 functional health facilities, comprised of 285 hospitals, 834 health centres and 6700 dispensaries, with the government being the major provider of health services by owning and running 70.6% of all health facilities across the country. The head of the health system is the Tanzanian Ministry of Health, Community Development, Gender, Elderly and Children (MoHCDEC), whose work is to oversee and facilitate the provision of health services in an easily accessible, good quality, affordable, sustainable and gender sensitive manner.[22]

In Tanzania, leprosy control falls under the responsibility of the NTLP whose activities started in 1977. The NTLP works under the Epidemiology and Disease Control Unit in the Department of Preventive Services of the Ministry of Health. It is a single entity that controls and ensures free provision of tuberculosis (TB) and leprosy services in Tanzania and has three major control strategies, including case finding, diagnosis and treatment services.[23] The NTLP is responsible for facilitating diagnosis and treatment for patients with TB and leprosy as early as possible, to reduce the incidence and prevalence of these diseases.

Administratively, the NTLP operates at three levels.[22] These generally follow the national, regional and district lines, but with some exceptions such as Dar es Salaam. Overall coordination and management of the TB and Leprosy Program at the regional and district level is

Figure 1. Map of Tanzania showing Mwanza, Movomero, Morogoro and Lindi regions.[21]

performed by the regional TB and leprosy coordinators (RTLCs) and district TB and leprosy coordinators (DTLCs) respectively. Zanzibar operates with a separate TB and Leprosy Control Program, but with a similar structure as the mainland.[23,24] The DTLCs compile all information regarding TB and leprosy and share this quarterly with the RTLC. It is the responsibility of each RTLC to compile and review all reports from the districts, and to create a regional report which is submitted to the NTLP on a quarterly basis.

SAMPLE AND SELECTION CRITERIA

We included data from all leprosy patients registered in the NTLP database from January 1, 2015 to December 31, 2019, and analyzed the epidemiological indicators. Records that were duplicates and those with incompatible patient information were excluded.

For the case detection delay estimation, 50 recently diagnosed patients, preferably within six months prior to the date of the interview to minimize recall bias, gave consent to take part in the study. Those who refused to consent or who were below the age of 18 years old were excluded. Sampling was performed systematically based on availability of recently diagnosed patients in PEP4LEP study districts and Mwanza.

OUTCOME MEASURES

The following epidemiological indicators according to WHO global leprosy reports were evaluated;[25] these indicators determine the disease progression in relation to leprosy elimination in a given geographical area:

- Number of newly detected cases of leprosy.
- Proportion of female cases among the new cases.
- Proportion of MB cases among the new cases.
- Proportion of new leprosy cases with grade 2 physical disability at the time of diagnosis.
- Proportion of new leprosy cases in children under 15 years old (at the regional level).

All rates were calculated with a common denominator of one million inhabitants according to the most recent WHO global leprosy report.[25] According to WHO, leprosy disability is an impairment of body function (loss of sensation) and structure (visible deformity or damage) as a consequence of leprosy disease.[22] Three grades are known, grade 0 (G0D) no deformity, grade 1 (G1D) loss of sensation and grade 2 (G2D) visible deformity. G2D at time of diagnosis is an indicator of case detection delay.

CASE DETECTION DELAY

A questionnaire designed for the PEP4LEP project was used to determine case detection delay, defined as the period between onset of first signs and symptoms of leprosy and the time of diagnosis, the questionnaire was developed according to a mixed methods cultural validation study.[26] This measure comprises both the "patient delay" and "health-system delay", as defined by Muthuvel *et al.*[27] A trained health worker (either a registered nurse or clinician) conducted the questionnaire guided interview with included patients. Questions included: delay of diagnosis, reasons for delay, symptoms sequencing in a descending manner from the first occurring to last before the leprosy diagnosis was made, as well as all steps taken during the course of illness until the time of diagnosis.[28] The questionnaire encompasses two annexes: a set of clinical photos of leprosy signs and a context-specific calendar indicating important local dates. The delay of diagnosis was determined as the difference between the time in months when the diagnosis was made and the time in months when the patient noticed the first sign/symptom. The questionnaire is online available via the international leprosy knowledge centre Infolep: https://www.leprosy-information.org/resource/case-detection-delay-questionnaire.[29] Since the delay in diagnosis was based on patients' memories, this is subject to recall problems; participants received their diagnosis at most six months before their inclusion date.

STATISTICAL ANALYSIS

Data from the 50 patients interviewed to assess the leprosy detection delay was analysed using SPSS version 26. A descriptive analysis was performed on all variables presented in absolute and relative frequencies by sex, age group, type of leprosy and disability grade. The chi-square test was used for association measures and confidence intervals of results were calculated; results were considered statistically significant at $p < 0.05$.

ETHICAL CONSIDERATIONS

The study activities are a component of the baseline survey for the PEP4LEP study.[8] The PEP4LEP project in Tanzania was approved on 17 June 2019 by the National Institute for Medical Research (NIMR) of Tanzania (reference number: NIMR/HQ/R.8c/Vol.1/1530). The

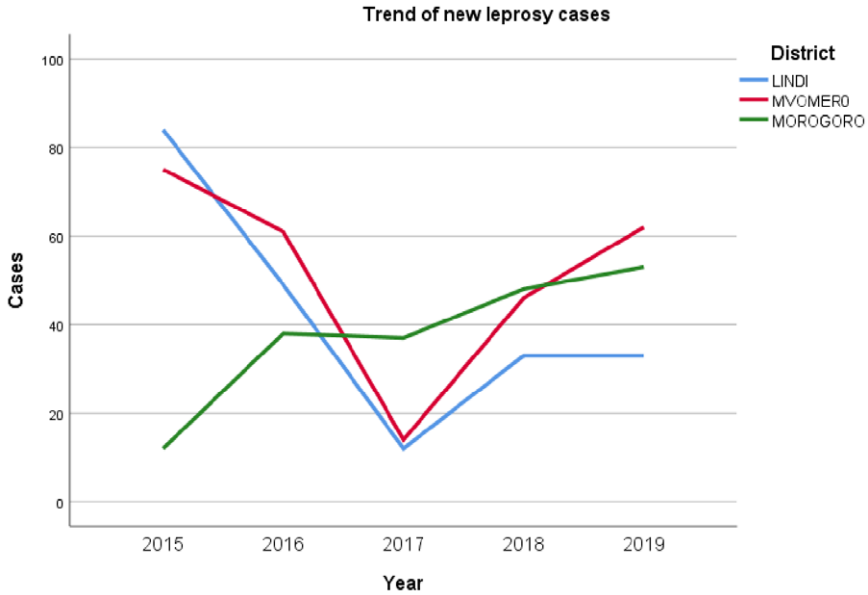

Figure 2. Trends in new case detection of leprosy in Lindi, Mvomero and Morogoro per year (2015–2019).

PEP4LEP project is registered at The Netherlands Trial Register, registration date 10 September 2018, NL7294 (NTR7503).[30]

Results

LEPROSY EPIDEMIOLOGY

Between 2015 to 2019, 657 new leprosy patients were registered in the NTLP database from the three PEP4LEP study districts in Tanzania: Morogoro, Mvomero and Lindi (Tables 1 and 2). Female cases were 247 (37.6%), the number of MB leprosy cases among newly diagnosed patients was 516 (78.5%) and in total 24 (3.7%) children with leprosy were registered. On average, Lindi had more new cases per million population (194.4) as compared to the other districts, although a decline was observed after 2015 (Figure 2). A similar trend was observed in Mvomero, with a decline after 2015, followed by an increase after 2017, while new leprosy cases have been increasing over the 5 year period in Morogoro. It also counted more female cases (98, 51.6%) and child cases (11, 5.2%). Of all registered cases Morogoro had more MB registered leprosy cases, 177 (94.1%) compared to 229 (88.8%) and 110 (52.1%) in Mvomero and Lindi respectively. Overall, there were significantly more MB than PB leprosy patients ($p < 0.001$) and more male than female patients ($p = 0.011$) in all districts; trends showed a significant decrease of paucibacillary cases in all districts from 2015 to 2019 ($p = 0.001$). G2D was recorded in 5 patients over this period, all of which were living in Lindi, which is equivalent to 4.5 per million population.

There were more males registered in the Mvomero and Morogoro districts, with almost equal male-female ratio in Lindi (51.6% were females). Over the 5-year period, Mvomero registered a total of 258 (39.3%) patients, Lindi 211 (32.1%) and Morogoro (rural) had the lowest number of new cases with 188 (28.6%). MB leprosy cases were more often seen (78.5%) than PB leprosy cases, with a clear difference in Mvomero and Morogoro districts where many

Table 1. Yearly leprosy indicators per study district for Lindi, Mvomero and Morogoro, 2015–2019

Year	Population	New cases detected	New cases per million population	Female cases (%)	MB cases (%)	Child cases (%)	G2D cases (%)	G2D per million population
				Lindi				
2015	220,510	84	380.9	49 (58.3)	30 (35.7)	5 (5.6)	4 (4.8)	18.1
2016	224,920	49	217.9	7 (14.3)	19 (38.8)	4 (8.2)	1 (2.0)	4.4
2017	215,327	12	55.7	11 (91.7)	7 (58.0)	0	0	0
2018	200,149	33	164.9	14 (42.4)	23 (70.0)	0	0	0
2019	224,568	33	146.9	17 (51.5)	31 (94.0)	2 (6.1)	0	0
				Morogoro				
2015	282,658	12	42.5	6 (53.3)	10 (83.3)	-	0	0
2016	324,264	38	117.2	15 (39.0)	31 (100)	-	0	0
2017	324,275	37	114.1	11 (29.7)	36 (97.3)	0	0	0
2018	327,913	48	146.4	20 (41.7)	47 (97.9)	6 (12.5)	0	0
2019	336,465	53	157.5	13 (22.4)	53 (100)	4 (7.5)	0	0
				Mvomero				
2015	358,961	75	208.9	24 (32.3)	60 (80.0)	-	0	0
2016	344,645	61	177.0	26 (42.6)	48 (78.7)	-	0	0
2017	355,536	14	39.4	3 (21.4)	13 (93.0)	1 (7.1)	0	0
2018	364,028	46	126.4	10 (21.7)	46 (100)	1 (2.2)	0	0
2019	373,223	62	166.1	21 (33.9)	62 (100)	1 (1.6)	0	0

Abbreviations: MB: multibacillary; G2D: grade 2 disability.

Table 2. Leprosy epidemiological indicators for Lindi, Morogoro and Mvomero districts in Tanzania, 2015–2019

District	Total new cases detected	Average yearly new cases per million population	Female cases (%)	MB cases (%)	Child cases (%)	G2D cases (%)	Average yearly G2D cases per million population
Lindi	211	194.4	98 (51.6)	110 (52.1)	11 (5.2)	5 (2.4)	4.5
Morogoro	188	117.8	65 (34.6)	177 (94.1)	10 (5.3)	0	0
Mvomero	258	143.6	84 (30.4)	229 (88.8)	3 (1.2)	0	0

Abbreviations: MB: multibacillary; G2D: grade 2 disability.

patients with MB leprosy (88.8% and 94.1% respectively) were detected, but an almost equal ratio was seen in Lindi (52.6%), see Figure 3.

In total, there were 15 registered leprosy cases who returned after defaulting medication, 14 (93.3%) of which were from Lindi district, one from Mvomero district and none from Morogoro district. Of the defaulting cases who did not complete their MDT regimen, 7 (46.7%) had MB leprosy and 8 (53.3%) had PB leprosy. There were a further 15 relapse cases after completion of medication, among those 12 (80.0%) were from Lindi District, 3 (20.0%) were from Mvomero and none from Morogoro district. Of these cases, 11 (73.3%) had MB leprosy and 4 (26.7%) had PB leprosy.

MB leprosy was found significantly more in males ($p < 0.001$) whereby out of 374 males, 362 (96.8%) had MB leprosy compared to 126 (46.8%) of all females (Figure 4). Both G1D and G2D at the time of diagnosis were significantly higher in females ($p < 0.001$). G2D was reported in 5 (0.8%) patients approximating around 4.5 G2D cases per one million population, all of whom were females residing in Lindi.

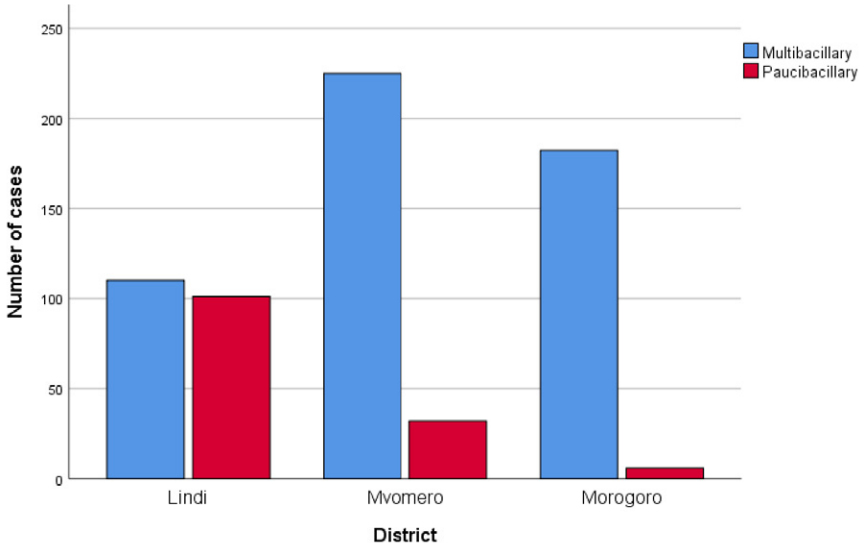

Figure 3. Leprosy subtype – World Health Organization classification in Lindi, Mvomero and Morogoro (2015–2019).

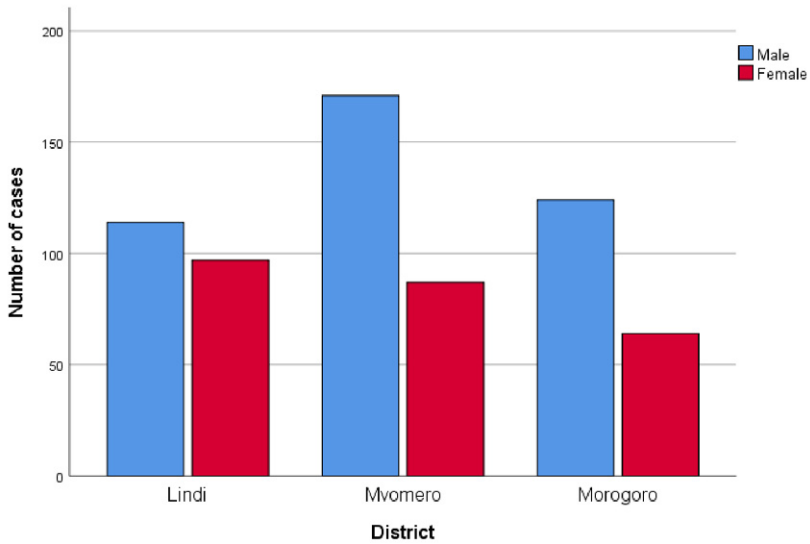

Figure 4. Sex distribution of leprosy cases in Lindi, Mvomero and Morogoro.

Among the proxy indicators for transmission of *M. leprae* is the new leprosy case detection in children. Across the region where the three included districts are located, Lindi had a total of 9 (6.8%) children diagnosed with leprosy in 2015–2016, while Morogoro in year 2018–2019 recorded 10 (7.2%) children with leprosy. Mvomero recorded the lowest number of child cases 3 (2.5%) between 2017–2019. Comparing the two regions where the three districts are located,

Table 3. Case detection delay for leprosy diagnosis

Characteristics	*n*	Mean case detection delay (months)	95% CI for mean		Median case detection delay (months)	Range	
			Lower bound	Upper bound		Min	Max
Districts							
Ifakara	30	23.3	14.9	31.7	17.5	0	93
Morogoro							
Nyamagana	6	56.0	31.7	80.3	54.0	28	82
Mwanza							
Mvomero	14	26.6	16.9	36.3	21.0	4	53
Sex							
Female	16	35.5	21.9	49.1	33.5	4	93
Male	34	24.7	17.1	32.2	19.0	0	81
Clinical subtype							
PB	12	22.5	9.2	35.8	19.5	4	82
MB	38	29.9	22.1	37.8	27.5	0	93
Disability grade							
G0D	16	16.9	11.6	22.1	16.0	4	45
G1D	16	27.8	14.3	41.3	25.0	2	82
G2D	18	38.4	25.5	51.4	35.5	0	93
Total	50	28.1	21.5	34.7	21.5	0	93

Abbreviations: PB: paucibacillary; MB: multibacillary; G0D: grade 0 disability; G1D: grade 1 disability; G2D: grade-2 disability; CI: confidence intervals; max: maximum; min: minimum; *n*: number.

the trends show a decrease of child cases in the year 2016, counting 4 (2%) and 3 (1%) for Lindi and Morogoro, respectively. In 2017, Lindi region recorded 6 (5.2%) new leprosy child cases while Morogoro region counted 2 (8.7%), in 2018 Morogoro region had 6 (3%) new child cases.[10–13]

CASE DETECTION DELAY

For delay of diagnosis, 50 patients with leprosy were interviewed who were diagnosed between January and December 2019 (Table 3). Of these patients, 44 (88.0%) were from Morogoro region (which includes Mvomero) and 6 (12.0%) were from Mwanza. There were 16 (32.0%) females, 38 (76.0%) MB leprosy cases and 18 (38.4%) had G2D at time of diagnosis. All 50 patients were adults over the age of 18 years, and the mean age was 46.0 years. A total of 38 (76.0%) experienced their first sign or symptom more than a year prior to diagnosis. The mean time of the occurrence of the first symptom, calculated back from the moment of diagnosis, was 28.1 (95% CI 21.5–34.7) months, with a median of 21.5 months, a minimum of 0 months and maximum of 93 months. A total of 24 patients (48.0%) reported to have visited the health centre 2 times before the diagnosis of leprosy was made, 11 (22.0%) attended a clinic once and 15 (30.0%) attended the health centre 3 times or more before being diagnosed. The mean number of visits made to a health centre by the 50 patients before they received the diagnosis of leprosy was 2.7 (95% CI: 2.03–3.29), and the mean time when the patients received their leprosy diagnosis was 11 months after their first health facility visit.

The most commonly reported first symptoms were skin patches in 31 (62.0%) patients, while 8 (16.0%) had loss of sensation and numb hands and feet, 8 (16.0%) had nodules, 2 (4.0%) experienced swelling and 1 (2.0%) had a painless ulcer. The majority of patients (82.0%) reported to have progressed to 2 symptoms and 27 (54.0%) had progressed to having 3 different symptoms before the diagnosis was made. Of those patients who reported 3 symptoms

before they were diagnosed with leprosy, 5 (18.5%) had painless wounds, 5 (18.5%) had sensitivity loss in hands and/or feet, 4 (14.8%) had enlarged nerves, 4 (14.8%) had loss of sensation of the skin, 3 (11.1%) experienced swelling, while skin patches and absorption of fingers and toes were reported by 1 patient each.

Half of the patients who attended a health facility within the first twelve months from occurrence of their first symptoms had a skin patch with loss of sensation as their first symptom. In contrast, 6 out of 8 (75.0%) of those who had nodules as their first symptom had attended a health facility more than 5 years after the onset of their symptoms. There were 10 (20.0%) patients who reported having tried self-treatment after noticing their first symptoms and 8 (16.0%) reported having gone to a traditional healer first.

There were 15 (30.0%) patients who received their diagnosis within 12 months after the onset of symptoms, while the other 35 (70.0%) patients received their diagnosis more than 12 months after the onset of first symptoms. MB leprosy was more frequently seen in males with G2D.

Discussion

This study aimed to describe the (leprosy) health system in Tanzania, to establish a trend of epidemiological indicators of leprosy in three districts and to determine the average case detection delay. Reliable epidemiological data on leprosy can be difficult to retrieve because of various reasons.[31] Although the three districts are located in two border regions, records showed some variation on leprosy detection and patient characteristics when compared to the population of the respective districts. The higher detection rate in Lindi compared to the two districts of Morogoro region and the higher number of MB patients in the two districts of Morogoro compared to Lindi could be caused by cultural differences that may influence the health seeking behavior of the community.[32] While there were a few child cases reported in each district between 2015–2019, some data were unavailable for certain years during this period and these figures should be reported more closely moving forward. As of 2019, all three districts remain highly endemic for leprosy (ranging from 117.8 to 194.4 new cases per million population). Overall, the number of leprosy cases recorded each year in the 5-year retrospective period decreased in Lindi and Mvomero, while in Morogoro the number of new cases increased over this period. However, these new case trends varied in Lindi and Mvomero, with higher numbers of cases recorded in year 2015 and 2016 and subsequently lower numbers in 2017, followed by a slight increase in 2018 and 2019. This could be due to the effect of the leprosy campaign and notification activities, particularly during the implementation of the Leprosy Post Exposure Prophylaxis (LPEP) program, which took place from 2015 to 2018 in both Morogoro and Lindi region.[33] Although the activities were carried out in different districts, the interaction among people living in the same society may have had an effect (such as raised leprosy awareness) in other districts of the same region.

There were significantly more MB leprosy cases observed in males than females, with a three to one ratio overall, a finding also observed in a study by Schreuder *et al.*[34] The reason for this may be the higher tendency of females to seek medical attention earlier than males, leading to earlier diagnosis.[35,36] In this study, leprosy disabilities were observed more in the case detection delay component of the study than figures recorded in the national TB and leprosy database, which may be due to under reporting of disabilities in the database. Females had significantly more disabilities than males, this is similar to the findings by Peters *et al.* in Southeastern Nigeria, who also reported a higher proportion of disability among the female patients.[37] A different observation was reported by Moschioni *et al.*[38] in Brazil, where

more disability among males was observed. A possible explanation for this observation in our setting is the engagement of females in activities such as cooking and farming, which may increase the chance of injury especially when the patient has reduced peripheral sensation. Peck *et al.* reported varying sex differences in the incidence of people getting burns according to age, region and national income category; they stated that studied women suffered from more burns than men in Ethiopia.[39]

Delay in leprosy diagnosis is not uncommon in leprosy endemic areas and is associated with many factors that may vary between communities.[20] Health system delay as a result of lack of leprosy knowledge among health workers could be one of the contributing factors.[27] This study revealed a mean number of patient visits to the health facility of 2.7 before receiving the leprosy diagnosis, and around one third of the patients reported to have visited a health facility three times or more before being diagnosed. This finding was in line with a study performed by Souza *et al.* in Brazil, who reported that the majority of patients (70%) made up to four visits to a health facility before they were diagnosed to have leprosy.[14] Higher numbers of visits were reported by Zhang *et al.* in China, who reported a mean number of health seeking actions of 7.2 from the time the patient was aware of their first symptom.[9] They also reported that out of 88 patients, 23 were diagnosed at their first visit of which 22 patients were diagnosed at a dermatology clinic. In China, the leprosy incidence is lower; health workers may be less familiar with the disease in areas which have a lower endemicity.[31] Knowledge on leprosy signs and symptoms is vital among the peripheral practicing health workers, particularly in high endemic areas, but this is often lacking.[40]

In this study, we found that 23 (46.0%) of all patients did not opt to visit the health facility as their first action upon the occurrence of their first symptoms. Of those, 9 (39.0%) visited a traditional healer first, 7 (30.5%) opted for self-treatment and 7 (30.5%) did not take any action. This could be caused by a lack of awareness of patients on first signs and symptoms as well as on when and where to seek medical attention. This was similar to the findings of the study by Zhang *et al.* who reported lack of knowledge on the illness and waiting for self-healing of the lesion in 93.1%, with 14.8% reportedly taking self-medication after noticing their first symptoms.[17] High levels of stigma and the use of traditional medicine was reported as one of the reasons for delaying visiting to the health facility in Ethiopia.[41] In this study, patients who opted for a step of action other than visiting a health facility had a longer delay in diagnosis compared to the majority of those who had gone to the health facility at first.

Leprosy diagnosis delay is still a problem in both endemic and non-endemic regions. A literature review by Dharmawan *et al.*, including 27 papers from 12 countries, described a median delay in detection ranging from 12 to 36 months and a mean delay of 11.5 to 64.1 months.[20] Urgesa *et al.*, who used an Ethiopian version of the for PEP4LEP designed case detection delay questionnaire in Ethiopia, found a median delay of 12 months and a mean delay of 22 months, with a maximum delay of 96 months.[42] Moreover, in a recent systematic review that collected patient data from several low-endemic countries, the mean case detection delay was 31.4 months.[43] These findings are in line with our study, whereby the mean delay in diagnosis in months was found to be 28.1 months, with 70% of all patients receiving their leprosy diagnosis after the first year from the onset of their first symptoms. This indicates the need for increased activity of the leprosy elimination programs in these areas. Moreover, strengthening of leprosy awareness at a community level and among primary health workers is needed in addition to other strategies, such as active case finding and chemoprophylaxis for leprosy.

Previous evidence suggests that the longer the correct diagnosis is delayed, the higher the chances are for the development of disabilities.[44] This was also noted in our study whereby all patients with G2D at time of diagnosis had their diagnosis delayed for more than 12 months from the onset of their symptoms. This was also observed by Shumet *et al.* who reported an overall prevalence of disability of 65.9% from all categories of patients (40.2% G1D and 25.7% G2D), reporting a direct association between the delay of diagnosis with the disabilities caused by leprosy.[45] A study by Gómez *et al.* in Colombia reported 14.9% of patients with disabilities at the time of diagnosis with a mean delay in diagnosis of 33.5 months.[46]

The results from this study were collected as part of the Tanzanian baseline survey component of the PEP4LEP study. One of the strengths of this study was that data collection was conducted by researchers from the study area, which allowed for greater access to and a good interpretation of information with regards to hospital records and health system structure. On the other hand, one of the limitations encountered was absence of case detection delay information for the Lindi PEP4LEP study district. There was also a much higher disability rate observed in the case detection delay component compared to the 5-year epidemiology data from each district. Although this may be due to underreporting of disability grade in national TB and leprosy database, it must nevertheless be considered when discussing how representative this sample is and should be explored further using PEP4LEP study data.

Conclusion

This study described the trend of new cases of leprosy in the three districts over a five year period, with a gradual increase observed in Morogoro and a relatively high mean leprosy detection delay of 28.1 months overall. This indicates the need for a prompt and a swift invigoration of the leprosy elimination programs in these areas. Strengthening of leprosy awareness at a community level and among primary health workers is needed in addition to other strategies, such as active case finding and chemoprophylaxis for leprosy, and may contribute to zero transmission, zero disease and zero disability.

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Contributorship

All co-authors are involved in the PEP4LEP study. NM drafted the manuscript and analysed the data. NM collected the field data. All co-authors reviewed the draft and provided comments.

Patient consent

Consent was collected from all study participants interviewed.

Data sharing statement

The data set generated and analysed during current study will be stored for a period of 25 years according to the European Union regulation 536/2014 considering clinical medication related research projects and will be made available on reasonable request.[47]

Conflict of interest

All authors declared no conflict of interest.

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