Lepr Rev (2022) **93,** 184–196 doi:10.47276/lr.93.3.184

Epidemiological trends of leprosy and case detection delay in East Hararghe Zone, Ethiopia: A baseline survey

Ephrem Mamo[a,b], Kidist Bobosha[b], Mengistu Legesse[a], Fufa Daba[c], Kitesa Debelo[c], Taye Leta[d], Thomas Hambridge[e], Anne Schoenmakers[e,f], Robin van Wijk[e,f], Christa Kasang[g], Liesbeth Mieras[f] & Jan Hendrik Richardus[e]

[a]*ALIPB, Addis Ababa University, Ethiopia*
[b]*AHRI, Ethiopia*
[c]*GLRA, Ethiopia*
[d]*Ministry of Health, Ethiopia*
[e]*Erasmus MC, University Medical Centre Rotterdam, Rotterdam, The Netherlands*
[f]*NLR, The Netherlands*
[g]*DAHW, Germany*

Submitted 8 March 2022; Accepted 14 July 2022

Summary

Objectives Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and one of the world's most neglected tropical diseases. The post-exposure prophylaxis for leprosy study (PEP4LEP) compares two integrated skin-screening approaches combined with single dose rifampicin administration to contacts of leprosy patients. The aim of this baseline survey was to describe the epidemiological trends of leprosy and estimate case detection delay in the Ethiopian study districts before the start of the intervention.

Methods The study was conducted in three districts of East Hararghe zone, Oromia Region, Ethiopia. We applied descriptive retrospective study design to describe epidemiological trends of leprosy between 2010 and 2019. Fifty patients diagnosed in the six months prior to their inclusion in the study were interviewed to establish the case detection delay at baseline. The healthcare delivery system and National Leprosy Control Program are also described.

Results Trends in the number of new leprosy patients detected decreased slightly over the past ten years, although the number of new child cases increased overall, suggesting ongoing transmission. The mean case detection delay was 22.4 months (95% CI: 18.6–26.3), while the median was 19.5 months. The mean patient and health system delay were 19.6 months (95% CI: 15.8–23.4) and 2.6 months (95% CI: 1.5–3.6), respectively.

Correspondence to: Ephrem Mamo Gebrehiwot, ALIPB, Addis Ababa University, Ethiopia & AHRI, Ethiopia (Tel.: +251910 40 68 03; e-mail: ephremmamo2015@gmail.com)

Conclusion Considerable leprosy case detection delays were found in the PEP4LEP study districts in Ethiopia. Efforts to reduce delay and interrupt the transmission should focus on integrating prevention and active case finding, contact tracing and providing post-exposure prophylaxis to contacts of leprosy patients.

Keywords: Leprosy, case detection delay, chemoprophylaxis, indicators, East Hararghe, Ethiopia

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* (*M. leprae*) and persists as a high endemic disease mainly in India, Brazil, Indonesia and parts of sub-Saharan Africa, such as Ethiopia. It is a neglected tropical disease (NTD) which can cause permanent physical impairments if left untreated and commonly leads to stigmatisation and discrimination.[1] Despite a declining prevalence worldwide over recent decades following the introduction of multidrug therapy (MDT), a large and relatively stable number of new cases is still detected annually.[2] In 2020, the World Health Organization (WHO) reported 127,396 new leprosy cases globally, with a case detection rate of 16.4 per million population.[3] However, these figures were much lower compared to the previous year with a global reported incidence of 202,185, which is likely attributable to the COVID-19 pandemic and the subsequent control measures that interrupted case finding activities.[3,4]

Out of the 23 WHO global leprosy priority countries, Ethiopia had the seventh highest number of reported cases globally in 2020; the second highest leprosy incidence in Sub-Sahara Africa.[3] In Ethiopia, leprosy patients are mainly detected through passive case detection in all regions following the integration of leprosy management into the general health system.[5] The number of new cases detected has decreased over the past ten years, from 4430 in 2010 to 2591 in 2020.[6] However, these figures are expected to be much higher if active case detection and accurate diagnostic procedures were incorporated the National Tuberculosis and Leprosy Control Program (TBLCP).[7,8]

Among the 2591 new leprosy cases reported in 2020, 1648 (55.8%) had MB leprosy, 384 (13.0%) had grade two disabilities (G2D) and 390 (13.2%) were children below the age of 15 years, with 55 (14.1%) of these children presenting with G2D.[3] There are pocket areas that report significantly higher numbers of cases annually in Ethiopia compared to other areas.[9] Oromia region had the highest number of leprosy cases reported, which accounts for around half of all leprosy patients in Ethiopia.[10]

The administration of single dose rifampicin post-exposure prophylaxis (SDR-PEP) to contacts of leprosy patients is among the strategies proposed to reduce transmission of *M. leprae*, which has previously shown to effectively reduce the risk of developing the disease in these individuals.[11] Since 2018, the WHO recommends chemoprophylaxis with SDR-PEP in the "Guidelines for the Diagnosis, Treatment and Prevention of Leprosy".[12]

Delay in case detection and treatment provision are among the major risk factors for transmission to other individuals, as well as for the development of irreversible physical disabilities.[13–17] There are many barriers to achieving timely detection of leprosy patients, including religious or cultural beliefs, social stigma or internalised stigma, lack of education or awareness, fear of isolation within the community and lack of knowledge among health staff.[18–21] To identify the most feasible ways to interrupt the transmission of *M. leprae* and enhance timely case detection, a large-scale research project called PEP4LEP was designed.[22]

Figure 1. Ethiopia map showing East Hararghe Zone.[25]

The PEP4LEP study is a cluster-randomised implementation trial in Ethiopia, Mozambique and Tanzania comparing two interventions of integrated skin-screening of contacts of leprosy patients combined with SDR-PEP distribution.[22] Before implementing the PEP4LEP study in Ethiopia, it is necessary to describe the trends in leprosy indicators and assess the baseline case detection delay in the study districts. This baseline survey is an integral part of the PEP4LEP project and aims: (1) to describe the epidemiological trends of leprosy in East Hararghe Zone between 2010 and 2019; and (2) to estimate the case detection delay in the PEP4LEP study districts before the start of the study intervention. The healthcare delivery system and National Leprosy Control Program of Ethiopia are also described.

Material and methods

STUDY LOCATION

This baseline study was conducted in the East Hararghe zone of Oromia region in March, 2020. East Hararghe zone is located approximately at 530 km from the capital city of Ethiopia, Addis Ababa (Figure 1). It is a densely populated zone with a total population of more than 3.5 million. East Hararghe is among the High Leprosy Burden (HLB) zones of Ethiopia. Leprosy mapping conducted in 2014/2015 revealed that 14 out of 22 districts of the zone were HLB.[9] This study was undertaken in three districts of the HLB area of East Hararghe Zone: Midega, Jarso, and Girawa.

STUDY SETTING

Healthcare delivery system of Ethiopia

Ethiopia has a three-tiered healthcare delivery system. The first is a district healthcare tier comprising of a primary hospital, health centres and their satellite Health Posts (HP) linked through referral systems, which form the Primary Health Care Unit (PHCU). The second tier constitutes a general hospital, while a specialised hospital forms the third tier of the healthcare delivery system. Health posts are staffed by health extension workers who provide community education, identify and refer patients suspected to have leprosy to health facilities for further investigation, perform contact tracing and screening, and search for cases that have been lost to follow-up. Health centres carry out all activities as HPs and also occasionally conduct intensified case finding, slit-skin smear examination for confirmation of leprosy diagnosis, provide leprosy MDT and prevention of disability (POD). Hospitals carry out activities as health centres and provide clinical care as indicated. The current method of case detection is mainly passive with a few periodic active outreaches.

National leprosy control program of Ethiopia

An organised leprosy control programme was established within the Ministry of Health (MoH) in 1956. The programme was vertical, well-funded and has made notable achievements in reducing the prevalence of the disease, especially after the introduction of MDT in 1983.[10,23] In the Ethiopian health care system, until 2001 leprosy was treated directly by leprosy dedicated personnel at leprosy specialised hospitals. The programme was fully incorporated into the general health services by the end of 2001 to guarantee that patients are diagnosed at an early stage and complete their MDT without developing disabilities.[24] Ethiopia is a federal state, where programming and policy implementation have contextual layers. The functions of the MoH consist of developing national policies and standards as well as providing national guidance and technical and financial support to Regional Health Bureaus (RHBs). At a sub-national level, the RHB's TBLCP is managed by TB and leprosy case teams under health promotion and disease prevention. Zonal health departments and district health offices are programme management structures at sub-regional levels.

STUDY DESIGN

A descriptive, retrospective study design was applied to describe epidemiological trends of leprosy control indicators between 2010 and 2019, and a cross-sectional study design was employed to determine the case detection delay at baseline.

To minimise recall problems in the case detection delay, only patients who were diagnosed with leprosy in the six months prior to their inclusion in the study were interviewed. Based on availability of recently diagnosed patients in PEP4LEP study districts, a systematic sample of 50 patients was included.

Retrospective data collection was used to describe epidemiological trends of leprosy control indicators. The following indicators were collected:

- Number of newly detected cases of leprosy (proxy of incidence).
- Proportion of new cases with each leprosy subtype.
- Proportion of females among new cases.
- Proportion of children under 15 years old among new cases.
- Proportion of new cases with G2D.

Leprosy subtypes were classified as either paucibacillary (PB) or multibacillary (MB) according to WHO guidelines:[12]

- PB case: a case of leprosy with 1 to 5 skin lesions, without demonstrated presence of bacilli in a skin smear;
- MB case: a case of leprosy with more than five skin lesions; or with nerve involvement (pure neuritis, or any number of skin lesions and neuritis); or with the demonstrated presence of bacilli in a slit-skin smear, irrespective of the number of skin lesions.

Disability grading of leprosy was defined according to the WHO definitions.[26]

DATA COLLECTION TO ESTIMATE CASE DETECTION DELAY

Detection delay is defined as the period between onset of first signs and symptoms of leprosy and the time of diagnosis, comprising of a "patient delay" and a "health-system delay".[20] Patient delay is defined as the period between the first noticed symptom by the patient and the first visit to any health care provider. Health-system delay is the period between the patient's first visit to any healthcare provider and confirmation of the diagnosis of leprosy.

Data collection on case detection delay was paper-based during a series of interviews with 50 recently diagnosed leprosy patients by a trained health worker using a semi-structured questionnaire which was designed for the PEP4LEP project.[22,27] The questionnaire consists of 10 questions and aims to collect information on the diagnosis delay, the reasons of delay, the signs and symptoms described and steps taken during the course of illness up until the time of diagnosis by a health professional. It also contains annexes as supplementary material: a set of clinical photos of leprosy signs and a local calendar listing important dates, such as festivities and religious celebrations to help the patient to recall the time of onset of first signs. A country and cultural context-specific version of the questionnaire was developed and validated and is available via the international leprosy knowledge centre Infolep: https://www.leprosy-information.org/resource/case-detection-delay-questionnaire.[22,28]

DATA MANAGEMENT AND ANALYSIS

Historical data were collected from routine surveillance systems of the TBLCP of the three districts. The data were checked, cleaned and entered using Epi Info Version 3.5.1 and exported to SPSS version 20, statistical software for analysis. The mean, percentage, tables and graphs were used to describe the trend characteristics of leprosy. The mean, median and standard deviation (SD) were used to describe diagnosis delay. Given the limited sample size, no association tests or multivariate analyses were performed to compare subgroups.

ETHICAL CONSIDERATIONS

This study was part of the baseline survey component of the PEP4LEP study protocol which was approved by the Institutional Review Board (IRB) of the Armauer Hansen Research Institute (AHRI), protocol number PO/15/19, and the National Research Ethics Review Committee of Ethiopia with reference number MoSHE/RD/4-1/1011/20.[22] A permission letter was obtained from the district health office and respective health facilities and written consent was obtained from the participants. All collected data were kept confidential and used for the study purposes only. The PEP4LEP project is registered at The Netherlands Trial Register, registration date 10 September 2018, NL7294 (NTR7503).[22,29]

Table 1. Yearly leprosy indicators per study district, East Hararghe Zone, Ethiopia, 2010 to 2019

Year	Population	New cases detected	New cases per million population	Female cases (%)	MB cases (%)	Child cases (%)	G2D cases (%)	G2D cases per million population
				Jarso				
2010	110,169	26	236	9 (34.6)	23 (88.5)	0 (0.0)	0 (0.0)	0
2011	119,601	36	301	14 (38.9)	35 (97.2)	3 (8.3)	0 (0.0)	0
2012	128,742	43	334	15 (34.9)	39 (90.7)	2 (4.6)	1 (2.3)	8
2013	129,825	37	285	14 (37.8)	37 (100.0)	1 (2.7)	0 (0.0)	0
2014	135,266	28	207	10 (35.7)	27 (96.4)	1 (3.6)	0 (0.0)	0
2015	141,079	34	241	9 (26.5)	29 (85.3)	12 (35.3)	0 (0.0)	0
2016	145,834	28	192	11 (39.3)	25 (89.3)	3 (10.7)	0 (0.0)	0
2017	150,877	43	285	15 (34.9)	38 (88.4)	7 (16.3)	0 (0.0)	0
2018	155,560	35	225	9 (25.7)	34 (97.1)	3 (8.6)	1 (2.9)	6
2019	160,791	23	143	8 (34.8)	21 (91.3)	2 (8.7)	0 (0.0)	0
				Midega				
2010	64,838	26	401	6 (23.1)	25 (96.2)	6 (23.1)	0 (0.0)	0
2011	70,103	34	485	11 (32.4)	31 (91.2)	1 (2.9)	0 (0.0)	0
2012	75,000	33	440	10 (30.3)	31 (94.0)	5 (15.2)	2 (6.1)	27
2013	80,604	32	397	9 (28.1)	30 (93.7)	4 (12.5)	1 (3.1)	12
2014	80,000	20	250	6 (30.0)	17 (85.0)	4 (20.0)	0 (0.0)	0
2015	85,106	24	282	8 (33.3)	19 (79.2)	3 (12.5)	0 (0.0)	0
2016	90,909	20	220	6 (30.0)	18 (90.0)	4 (20.0)	0 (0.0)	0
2017	94,828	22	232	7 (31.8)	15 (68.2)	5 (22.7)	1 (4.5)	11
2018	100,000	33	330	5 (15.1)	22 (66.6)	4 (12.1)	4 (12.1)	40
2019	104,682	25	239	10 (40.0)	24 (96.0)	7 (28.0)	0 (0.0)	0
				Girawa				
2010	285,714	74	259	16 (21.6)	72 (97.3)	2 (2.7)	0 (0.0)	0
2011	290,697	50	172	12 (24.0)	48 (96.0)	1 (2.0)	0 (0.0)	0
2012	294,118	30	102	9 (30.0)	27 (90.0)	2 (6.7)	0 (0.0)	0
2013	300,885	34	113	10 (29.4)	31 (91.2)	4 (11.8)	0 (0.0)	0
2014	308,823	21	68	5 (23.8)	19 (90.5)	3 (14.3)	1 (4.8)	3
2015	311,111	42	135	11 (26.2)	36 (85.7)	6 (14.3)	1 (2.4)	3
2016	316,326	31	98	3 (9.7)	25 (80.6)	1 (3.2)	0 (0.0)	0
2017	319,588	31	97	9 (29.0)	28 (90.3)	4 (12.9)	2 (6.5)	6
2018	325,581	28	86	4 (14.3)	24 (85.7)	2 (7.1)	2 (7.1)	6
2019	330,490	18	55	1 (5.5)	14 (77.8)	5 (27.8)	0 (0.0)	0

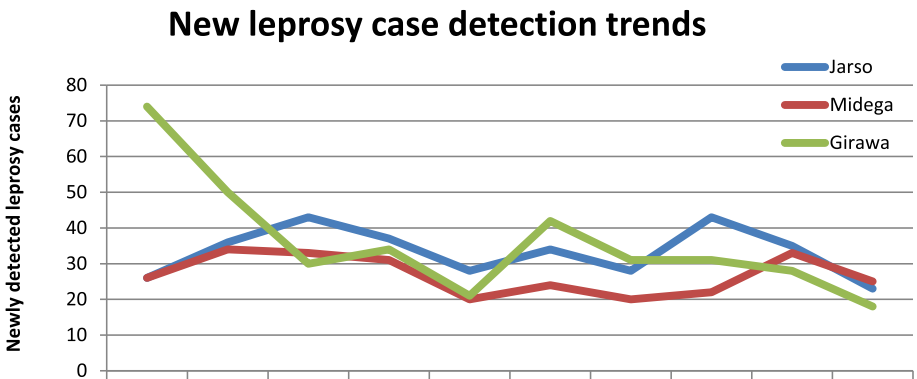
Abbreviations: MB: multibacillary; G2D: grade-2 disability.

Results

EPIDEMIOLOGICAL TRENDS OF LEPROSY IN THE STUDY DISTRICTS

The epidemiological indicators of leprosy cases in PEP4LEP study districts are shown below. Jarso had an estimated population of 160,791 people in 2019, while Girawa and Midega had 330,490 and 104,682 people, respectively. The numbers of female cases, G2D and MB cases have been relatively stable, while new cases of leprosy in children increased over the past decade (Table 1).

Between 2010 and 2019, a total of 333 new cases of leprosy were detected in Jarso, of which 308 (92.5%) were MB cases, 34 (10.2%) were children under 15 years of age, 114 (34.2%) were women and the average annual new case detection rate was 244.9 per million population. In Girawa, 359 new cases of leprosy were recorded, of which 323 (90.2%) were MB cases, 30 (8.4%) were children under 15 years of age, 79 (22.0%) were women and the average annual



	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Jarso	26	36	43	37	28	34	28	43	35	23
Midega	26	34	33	31	20	24	20	22	33	25
Girawa	74	50	30	34	21	42	31	31	28	18

Figure 2. New leprosy cases detected in East Hararghe Zone, Ethiopia, 2010 to 2019.

Table 2. Leprosy epidemiological indicators, East Hararghe Zone, Ethiopia, 2010 to 2019

Study 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
Jarso	333	244.9	114 (34.1)	308 (92.5)	34 (10.2)	2 (0.6)	1.4
Midega	268	327.6	78 (29.2)	232 (86.7)	43 (16.0)	8 (2.9)	9.0
Girawa	359	118.5	79 (22.2)	324 (90.2)	30 (8.4)	6 (1.7)	1.8

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

new case detection rate was 118.5 per million population. In Midega, a total of 268 new cases of leprosy were recorded, of which 232 (86.7%) were MB cases, 43 (16.0%) were children under 15 years of age and 78 (29.2%) were women, with an annual average new case detection rate of 327.6 per million population (Table 2). The numbers of new leprosy cases per district between 2010 and 2019 are also shown visually in the graph below, with the number of new patients detected decreasing slightly over the past ten years (Figure 2).

CASE DETECTION DELAY IN THE STUDY DISTRICTS

Characteristics of study participants

The socio-demographic characteristics of the 50 study participants show that the mean age was 35.9 years, with 6.0% under the age of 15 years (Table 3). Regarding the level of education, 64.0% of the respondents received no education, while 36.0% completed at least primary school. A majority of the study participants (96.0%) lived in rural areas. The average distance of their place of residence to a health facility was 9.6 km and the average number of people living under the same roof was 5.

Delay in the diagnosis of leprosy

In this study, among 50 cases 12 (24.0%) were female and 44 (88.0%) had MB leprosy. These characteristics are in line with the 10-year epidemiological data presented above. There were

Table 3. Case detection delay, East Hararghe zone, Ethiopia, 2020

Variable	*n* (%)	Mean case detection delay (months)	95% CI for mean		Median case detection delay (months)	Range	
			Lower bound	Upper bound		Min	Max
District							
Jarso	14 (28.0%)	24.0	14.0	34.0	17.0	3.0	60.0
Midega	16 (32.0%)	22.7	13.8	31.7	19.0	6.0	67.0
Girawa	20 (40.0%)	21.1	18.3	23.9	22.0	10.0	36.0
Sex							
Male	38 (76.0%)	22.3	18.5	26.2	21.5	7.0	60.0
Female	12 (24.0%)	22.7	10.9	34.6	18.0	3.0	67.0
Age group							
<15 years	3 (6.0%)	20.0	9.3	49.3	23.0	7.0	30.0
≥15 years	47 (94.0%)	22.6	18.6	26.6	19.0	3.0	67.0
Leprosy subtype							
PB	6 (12.0%)	13.5	5.5	21.5	12.0	6.0	26.0
MB	44 (88.0%)	23.7	19.5	27.8	20.5	3.0	67.0
Disability grade							
None	31 (62.0%)	23.0	17.9	29.0	20.0	3.0	67.0
G1D	14 (28.0%)	20.0	13.6	26.4	17.0	7.0	47.0
G2D	5 (10.0%)	23.6	11.8	34.1	25.0	14.0	36.0
Total	50	22.4	18.6	26.3	19.5	3.0	67.0

Abbreviations: PB: paucibacillary; MB: multibacillary; *n*: number; G1D: grade-1 disability; G2D: grade-2 disability; CI: confidence intervals.

45 (90.0%) patients who presented with no disability or G1D, while 5 (10.0%) patients had a G2D at the time of diagnosis. The overall mean case diagnosis delay was 22.4 months (95% CI: 18.6–26.3), while the median was 19.5 months. The largest contributor to case detection delay was patient delay, with a mean of 19.6 months (95% CI: 15.8–23.4), while the mean health system delay was 2.6 months (95% CI: 1.5–3.6). The maximum reported delay in this study was 67 months (Table 3).

The first symptoms experienced by most patients were skin lesions (64.0%), with an average onset of 25.5 months (95% CI: 21.4–29.6) before diagnosis, followed by sensory loss (14.0%) with an average onset of 25.1 months (95% CI: 20.4–29.8) before diagnosis. The first action taken by most of the patients was visiting a health facility (62.0%), followed by visiting a traditional healer (20.0%). Regarding the number of health facility visits before diagnosis, two-thirds of the included patients visited health facilities less than twice, while 12.0% visited health facilities more than three times before receiving the correct diagnosis. MB patients, patients with G2D and patients who visited a traditional healer had markedly longer detection delays.

Discussion

Leprosy remains a public health problem in many areas of Ethiopia. Our analysis of epidemiological trends of leprosy in East Hararghe Zone showed slightly decreasing trends in the number of new cases detected over the past ten years, with varying annual incidence rates in the three districts. Nevertheless, a higher incidence was recorded in all three study districts compared to the rest of the country and these remain categorised as HLB zones.[23,30] The method of case detection in the districts was mainly passive in the past 10 years, with few

periodic outreach activities, which may be a contributing factor for delayed diagnosis. This shows that interventions will still be necessary in order to decrease the incidence of leprosy in the intervention areas. In the current study, most registered cases had MB leprosy at the time of diagnosis, which is in line with another study in East Hararghe, Ethiopia reported that 90.9% of cases were MB type leprosy.[31] Other studies in Ethiopia also showed that the percentage of MB cases among newly detected leprosy cases has increased significantly since 2000.[23] Similar findings were also observed in other endemic countries.[32] This could be due to delayed presentation of patients to the health facility for diagnosis and/or due to delayed recognition by health workers and initiation of treatment.

The results from this study also showed that the rate of childhood cases among newly detected cases in the study districts has increased over the past ten years. This finding was supported by a recent study performed at national level including other rural parts of Ethiopia, as well as in other countries such as Sri Lanka and Yemen.[10,33–36] The percentage of child cases is higher when compared to China and Vietnam, as well as the global and national target of less than 5%.[2,36,37] A high proportion of childhood leprosy reveals an active circulation of bacilli, continued transmission in the community and lack of disease control by the health system in the districts.[13,38]

The number of new leprosy patients diagnosed with G2D is an indicator of late case identification. Our study found that the proportion of new cases with G2D was below the 5% threshold generally accepted by the WHO. However, the average grade 2 disability rate at the population level is higher than the WHO key target for 2030 (less than one new case with G2D per million inhabitants).[13]

In our study, the proportion of females among new cases was relatively low. This finding was supported in several previous studies.[39,40] This may indicate that females in the districts are more likely than males to experience barriers in getting correctly diagnosed.

We also conducted a cross-sectional study to measure the mean delay in diagnosis of leprosy. Here, we observed a mean case detection delay in the study districts of 22.4 months (95% CI: 18.6–26.3) and a median of 19.5 months. High levels of stigma and the use of traditional medicine were reported as one of the reasons for delaying visiting to the health facility in Ethiopia.[41] Our findings are in line with those of Urgesa *et al.* who first used the PEP4LEP questionnaire in Ethiopia and found a mean delay of 22 months, as well as with the findings of a study in India which reported a mean case detection delay of around 23 months.[22,42] We found lower delays than a recent systematic review by Hambridge *et al.* that reported 31.7 months in China and another study that reported a mean delay of 33.5 months in Colombia.[21,43]

Leprosy case detection delay is associated with a number of individual, socioeconomic, and community factors.[16,20,44] A recent review by Dharmawan *et al.* also found a clear correlation between case detection delay and increased disability.[44] The high disability rate in newly diagnosed leprosy patients represents a delay in diagnosis which may be due to patients presenting themselves at the health facility late in the course of the disease.[45] The fact that multiple visits to health facilities are needed, indicating misdiagnosis, can be caused by an inability of health workers to recognise the signs and symptoms of leprosy.[46] In this study, 75.0% of the patients were diagnosed one year after they noticed the first signs or symptoms of the disease. Overall, 38.0% of the respondents presented with disability at the time of diagnosis, which is supported by a recent pilot study in East Hararghe which reported 42%, but lower than a study in Central Ethiopia which reported 65.0%, and in a hospital based study in

Boru Meda in Ethiopia where 68.9% of the leprosy patients presented with disabilities.[42,45,47] This implies that further action is needed to improve early case detection and prevent disability.

The strength of this baseline study was that primary and secondary data were collected by local researchers with an understanding of the national health system and language. One important limitation to consider is potential recall problems in the case detection delay component, when patients try to remember the commencement of the signs and symptoms of leprosy. To minimise this, a standardised and validated questionnaire was used, and data collectors inquired further with the patient using memorable dates on a local calendar, such as festivities and religious celebrations. In addition, only recently diagnosed patients were included.

Conclusion

The epidemiological indicators presented here show that there is high leprosy endemicity in the study districts with many childhood cases still being reported, indicating that transmission of *M. leprae* is ongoing. Community based awareness raising on leprosy aimed at encouraging seeking medical care timely, training of health staff, as well as the implementation of an intervention aimed at early case detection, can help to reduce case detection delay and disability. Furthermore, the provision of chemoprophylaxis as part of the PEP4LEP skin-screening interventions could help interrupt the transmission of *M. leprae* in East Hararghe Zone.

Acknowledgements

The authors would like to thank the study participants who voluntarily participated in this study, the full research consortium and our funders European and Developing Countries Clinical Trials Partnership (EDCTP) and Leprosy Research Initiative (LRI).

Funding

This project is part of the EDCTP2 programme supported by the European Union awarded to NLR/LM (grant number RIA2017NIM-1839-PEP4LEP), and the Leprosy Research Initiative (LRI; www.leprosyresearch.org) awarded to NLR/LM (grant number 707.19.58). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Contributorship

All co-authors are involved in the PEP4LEP study. EM drafted the manuscript and analysed the data. EM, FD and KD 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.[48]

Conflict of interest

All authors declared no conflict of interest.

References

1. Manderson L, Aagaard-Hansen J, Allotey P *et al.* Social research on neglected diseases of poverty: continuing and emerging themes. *PLoS Negl Trop Dis*, 2009; **3**(2): e332. doi:10.1371/journal.pntd.0000332.
2. Meima A, Richardus JH, Habbema JDF. Trends in leprosy case detection worldwide since 1985. *Lepr Rev*, 2004; **75**(1): 19–33. doi:10.47276/lr.75.1.19.
3. World Health Organization. Global leprosy (Hansen disease) update, 2020: time to step-up prevention initiatives. *Wkly Epidemiol Rec*, 2021; **95**(36): 417–440. Available from: https://www.who.int/publications/i/item/who-wer9536.
4. World Health Organization. Global leprosy (Hansen disease) update, 2019: time to step-up prevention initiatives. *Wkly Epidemiol Rec*, 2020; **95**(36): 417–440. Available from: https://www.who.int/publications/i/item/who-wer9536.
5. Federal Democratic Republic of Ethiopia – Ministry of Health. *Guidelines for Clinical and Programmatic Management of TB, Leprosy and TB/HIV in Ethiopia*. 6th edn, 2017.
Available from: https://www.afro.who.int/sites/default/files/2019-04/Ethiopia-National%20guidelines%20for%20TB%2C%20DR-TB%20and%20Leprosy%20in%20Ethiopia%20-%20Sixth%20Edition.pdf.
6. World Health Organization. Global leprosy update, 2018: moving towards a leprosy-free world. *Wkly Epidemiol Rec*, 2019; **94**(35/36): 389–411. Available from: https://www.who.int/publications/i/item/who-wer9435-36.
7. Federal Ministry of Health Ethiopia. *Tuberculosis, Leprosy and TB/HIV Prevention and Control Programme Manual*. 4th edn, Addis Ababa, Ethiopia: FMOH, 2008.
8. Smith WC, van Brakel W, Gillis T *et al.* The missing millions: a threat to the elimination of leprosy. *PLoS Negl Trop Dis*, 2015; **9**(4): e0003658. doi:10.1371/journal.pntd.0003658.
9. Mohammed A. Tuberculosis and Leprosy prevention and control in Ethiopia. In: *Annual Master Report*. Addis Ababa, Ethiopia: German Leprosy Relief Association (GLRA), 2014.
10. Sori EA. Review on the burden of Leprosy in Ethiopia. *J Trop Dis*, 2019; **7**(2): 1000297. doi:10.4172/2329-891X.1000297.
11. World Health Organization. *Leprosy/Hansen Disease: Contact Tracing and Post-Exposure Prophylaxis*. 2020. Available from: https://apps.who.int/iris/handle/10665/336679.
12. World Health Organization. *Guidelines for the Diagnosis, Treatment and Prevention of Leprosy*. 2018. Available from: https://apps.who.int/iris/bitstream/handle/10665/274127/9789290226383-eng.pdf?ua=1.
13. World Health Organization. Global leprosy update, 2016: Accelerating reduction of disease burden. *Wkly Epidemiol Rec*, 2017; **92**(35): 501–519. Available from: https://www.who.int/publications/i/item/who-wer9235.
14. Barreto JG, Frade MAC, Bernardes Filho F *et al.* Leprosy in children. *Curr Infect Dis Rep*, 2017; **19**(6): 23. doi:10.1007/s11908-017-0577-6.
15. Shumet T, Demissie M, Bekele Y. Prevalence of disability and associated factors among registered leprosy patients in all Africa tb and leprosy rehabilitation and training centre (ALERT), Addis Ababa, Ethiopia. *Ethiop J Health Sci*, 2015; **25**(4): 313–320. doi:10.4314/ejhs.v25i4.4.
16. Van Veen NHJ, Meima A, Richardus JH. The relationship between detection delay and impairment in leprosy control: a comparison of patient cohorts from Bangladesh and Ethiopia. *Lepr Rev*, 2006; **77**(4): 356–365. doi:10.47276/lr.77.4.356.
17. Zia M, Anwar MI. Delayed diagnosis of neural signs of leprosy. *J Pakistan Assoc Dermatologists*, 2017; **27**(2): 183–186. doi:10.1590/abd1806-4841.201533963.
18. Engelbrektsson UB, Subedi M. Stigma and leprosy presentations, Nepal. *Lepr Rev*, 2018; **89**(4): 362–369. doi:10.47276/lr.92.1.11.
19. Price VG. Factors preventing early case detection for women affected by leprosy: a review of the literature. *Glob Health Action*, 2017; **10**(sup 2): 1360550. doi:10.1080/16549716.2017.1360550.
20. Muthuvel T, Govindarajulu S, Isaakidis P *et al.* I wasted 3 years, thinking it's not a problem: Patient and health system delays in diagnosis of leprosy in India: A mixed-methods study. *PLoS Negl Trop Dis*, 2017; **11**(1): e0005192. doi:10.1371/journal.pntd.0005192.
21. Gómez L, Rivera A, Vidal Y *et al.* Factors associated with the delay of diagnosis of leprosy in north-eastern Colombia: a quantitative analysis. *Trop Med Int Heal*, 2018; **23**(2): 193–198. doi:10.1111/tmi.13023.
22. Schoenmakers A, Hambridge T, van Wijk R *et al.* PEP4LEP study protocol: integrated skin screening and SDR-PEP administration for leprosy prevention: comparing the effectiveness and feasibility of a community-based intervention to a health centre-based intervention in Ethiopia, Mozambique and Tanzania. *BMJ Open*, 2021; **11**(8): e046125. doi:10.1136/bmjopen-2020-046125.

[23] Baye S. Leprosy in Ethiopia: Epidemiological trends from 2000 to 2011. *Adv Life Sci Heal*, 2015; **2**(1): 31–44.
[24] Feenstra P, Visschedijk J. Leprosy control through general health services-revisiting the concept of integration. *Lepr Rev*, 2002; **73**(2): 111–122. doi:10.47276/lr.73.2.111.
[25] Maps Ethiopia - Addis Ababa Ethiopia map. Available from: https://maps-ethiopia.com/addis-ababa-ethiopia-map.
[26] Rani Z. Leprosy elimination strategy. *J Pakistan Assoc Dermatologists*, 2007; **17**(1): 1–3. Available from: https://www.jpad.com.pk/index.php/jpad/article/download/675/648.
[27] de Bruijne ND, Urgesa K, Aseffa A *et al.* Development of a questionnaire to determine the case detection delay of leprosy: A mixedmethods cultural validation study. *PLoS Negl Trop Dis*, 2022; **16**(1): 1–16. doi:10.1371/journal.pntd.0010038.
[28] Infolep. Case Detection Delay Questionnaire. Cited 15 Jan 2022. Available from: https://www.leprosy-information.org/resource/case-detection-delay-questionnaire.
[29] Netherlands Trial Register. Trial NL7294 (NTR7503). PEP4LEP. Chemoprophylaxis for leprosy: comparing the effectiveness and feasibility of a skin camp intervention to a health centre based intervention. An implementation trial in Mozambique, Ethiopia and Tanzania. 2018. Available from: https://www.trialregister.nl/trial/7294.
[30] Mosam A, Todd G. Dermatology training in Africa: successes and challenges. *Dermatol Clin*, 2021; **39**(1): 57–71. doi:10.1016/j.det.2020.08.006.
[31] Urgesa K, Bobosha K, Seyoum B *et al.* Evidence for hidden leprosy in a high leprosy-endemic setting, eastern ethiopia: The application of active case-finding and contact screening. *PLoS Negl Trop Dis*, 2021; **15**(9): 1–12. doi:10.1371/journal.pntd.0009640.
[32] Doshi D, Balegar S, Bhushan Singh S, Mishra DK. Reasons of delay in diagnosis of leprosy: A cross sectional study. *IOSR J Dent Med Sci Ver I*, 2016; **15**: 2279–2861.
[33] Ramos JM, Ortiz-Martínez S, Lemma D *et al.* Epidemiological and clinical characteristics of children and adolescents with leprosy admitted over 16 years at a rural hospital in Ethiopia: A retrospective analysis. *J Trop Pediatr*, 2018; **64**(3): 195–201. doi:10.1093/tropej/fmx048.
[34] Ramos JM, Reyes F, Lemma D, Tesfamariam A, Belinchon I, Gorgolas M. The burden of leprosy in children and adolescents in rural southern Ethiopia. *Paediatr Int Child Health*, 2014; **34**(1): 24–28. doi:10.1179/2046905513Y.0000000073.
[35] Madarasingha NP, Senaviratne JKK. A study of household contacts of children with leprosy. *Ceylon Med J*, 2011; **56**(3): 112–114. doi:10.4038/cmj.v56i3.3602.
[36] Fine PEM. Global leprosy statistics: a cause for pride, or frustration? *Lepr Rev*, 2006; **77**(4): 295–297. doi:10.47276/lr.77.4.295.
[37] Shen JP, Gupte MD, Jiang C *et al.* Trends of case detection and other indicators of leprosy in China during 1985–2002. *Chin Med Sci J*, 2005; **20**: 77–82. Available from: https://pubmed.ncbi.nlm.nih.gov/16075742/.
[38] Nazario AP, Ferreira J, Schuler-Faccini L *et al.* Leprosy in Southern Brazil: a twenty-year epidemiological profile. *Rev Soc Bras Med Trop*, 2017; **50**: 251–255. doi:10.1590/0037-8682-0229-2016.
[39] Le W, Haiqin J, Danfeng H *et al.* Monitoring and detection of leprosy patients in Southwest China: A retrospective study, 2010–2014. *Sci Rep*, 2018; **8**(1): 11407. doi:10.1038/s41598-018-29753-4.
[40] Keita M, Soumah MM, Diané BF, Kamano K, Doumbouya A, Tounkara TM. Les états réactionnels au cours d'un régime de polychimiothérapie Anti lépreuse dans les sites de prise en charge de Lèpre de la ville de Conakry. *Bull ALLF*, 2014; **29**: 9–11. doi:10.1016/j.annder.2012.10.320.
[41] Bekri W, Gebre S, Mengiste A, Saunderson PRZS. Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non-disabled patients in three different settings in Ethiopia. *Int J Lepr Other Mycobact Dis*, 1998; **66**(1): 1–9. Available from: http://ijl.ilsl.br/detalhe_artigo.php?id=NDU5.
[42] Urgesa K, de Bruijne N, Bobosha K *et al.* Prolonged delays in leprosy case detection in a leprosy hot spot setting in Eastern Ethiopia. *PLoS Negl Trop Dis*, (accepted).
[43] Hambridge T, Nanjan Chandran SL, Geluk A, Saunderson P, Richardus JH. Mycobacterium leprae transmission characteristics during the declining stages of leprosy incidence: A systematic review. *PLoS Negl Trop Dis*, 2021; **15**(5): e0009436. doi:10.1371/journal.pntd.0009436.
[44] Dharmawan Y, Fuady A, Korfage I, Richardus JH. Individual and community factors determining delayed leprosy case detection: A systematic review. *PLoS Negl Trop Dis*, 2021; **15**(8): e0009651. doi:10.1371/journal.pntd.0009651.
[45] Abdela SG, Diro E, Zewdu FT *et al.* Delayed diagnosis and ongoing transmission of leprosy in the post-elimination era in Boru Meda hospital, Ethiopia. *J Infect Dev Ctries*, 2020; **14**(6.1): 10S–15S. doi:10.3855/jidc.11706.
[46] Abeje T, Negera E, Kebede E *et al.* Performance of general health workers in leprosy control activities at public health facilities in Amhara and Oromia States, Ethiopia. *BMC Health Serv Res*, 2016; **16**(1): 1–7. doi:10.1186/s12913-016-1329-2.

[47] Meima A, Saunderson PR, Gebre S, Desta K, Van Oortmarssen GJ, Habbema JD. Factors associated with impairments in new leprosy patients: the AMFES cohort. *Lepr Rev*, 1999; **70**(2): 189–203. doi:10.5935/0305-7518.19990022.

[48] European Commission. Guidelines to the rules on open access to scientific publications and open access to research data in horizon 2020. 2017. Available from: https://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-pilot-guide_en.pdf.