

The Ethiopian SORT IT Course

Delayed diagnosis and ongoing transmission of leprosy in the post-elimination era in Boru Meda hospital, Ethiopia

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Abstract

Introduction: Following the recommendation of the Global Leprosy Strategy, Ethiopia targeted to reduce the incidence of new leprosy cases, and the proportion with severe disability (grade 2) from 13.6% in 2016 to < 1% in 2020. This study assessed the clinical profile of new leprosy cases and the sequelae of previously treated ones 20 years after leprosy was eliminated as a public health problem in the country.

Methodology: Hospital based cross sectional study was conducted by reviewing the medical records of all leprosy patients seen at the dermatology clinic of Boru Meda Hospital from August to December 2018. The data were captured using a standard data collection form.

Results: Over the study period, 57 (27.4%) new cases and 151 (72.6%) previously treated cases were seen. The median age was 44 years (interquartile range 32-57). Among the newly diagnosed cases, two were under the age of 15 years, 51 (89.5%) were multibacillary and 34 (59.6%) had grade 2 disability. This included visual impairment in 10 (17.5%) and neurological complications in 44 (77.2%). Of the 151 previously treated cases, 104 (68.9%) presented with disabilities, including 97 (64.2%) with grade 2. Amongst previously treated cases, 130 (86.1%) had neurological complications. In addition, 53 (35.1%) had vision impairment.

Conclusions: This study showed evidence of ongoing leprosy transmission and delayed diagnosis in the country. This calls for operational research to determine the underlying reasons and provide ways forward. At the same time, the high burden of disabilities in previously treated cases should be addressed.

Key words: Post elimination; indicators; leprosy; Ethiopia.

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Introduction

Leprosy, caused by the *Mycobacterium leprae*, prevails in at least 122 countries. Globally, about 200,000 new leprosy cases - including approximately 18,000 in children are diagnosed annually, with many more hidden cases [1,2]. The diagnosis of leprosy is based on skin and neurologic examination, combined with microscopic examination of slit skin smears. Leprosy is the main cause of infectious disabilities mainly attributed to peripheral nerve damage, leading to loss of sensation and tissue damage from burns and repeated trauma. Over time, this can lead to self-amputation of the hands and feet. Blindness is another important complication [3]. Leprosy is curable and early treatment can prevent physical disabilities that have an impact on the individual's social and working

life [4,5]. In general, multibacillary cases have a higher risk of treatment complications and severe (*i.e.* grade 2) disabilities [6].

There has been a global reduction in the burden of leprosy since multidrug therapy was introduced more than three decades ago. However, the global target of one third reduction in new cases with grade 2 leprosy related disabilities set by the 2011–2015 Global strategy for further reducing the burden due to leprosy has not been achieved [2]. This prompted the World Health Organization (WHO) to launch a more comprehensive strategy, the 2016–2020 Global Leprosy Strategy “Accelerating towards a leprosy-free world”. This strategy was developed around three pillars that address governance, medical and social aspects of leprosy [2,7].

Leprosy has been identified as a public health problem in Ethiopia for the past five decades. In 2016, Ethiopia reported 3692 new cases, second in Africa to the Democratic Republic of Congo. The country is still on the WHO list of “global priority countries for leprosy” [8]. Although the leprosy elimination target of less than 1 case per 10,000 population has been reached at national level since 1999, progress in terms of reduction of new cases and leprosy-related complications has stalled for the last ten years [9]. Consequently, based on the Global Leprosy Strategy, a new national plan has been developed. The country targets include reducing the incidence of new leprosy cases and reducing the proportion of new leprosy cases with severe disability (grade 2) from 13.6% in 2016 to less than 1% in 2020 [9].

Given the weak health information system, the Ethiopian strategy also called for operational research to monitor progress towards the country’s targets [9]. This study will report on the mid-term progress (2018) related to three key program indicators in one of the five main leprosy referral hospitals in Ethiopia. Selected indicators include the number of childhood leprosy cases, the proportion of new cases with grade-2 disability and the proportion of new cases with multibacillary leprosy. These all point towards delays in diagnosis or ongoing transmission of the infection within the community [2].

One undervalued dimension of global and national leprosy elimination strategies is the chronic sequelae of previously treated leprosy cases. The care of such cases is complicated, as it requires rehabilitation services, trained professionals and specific equipment. To be able to organize such multidisciplinary care, detailed information on how common and to what extent these different complications occur is important. However, this information is currently lacking in Ethiopia.

This study was conducted to report on key program indicators amongst newly diagnosed leprosy patients and to provide a detailed assessment of leprosy-related complications of previously treated cases.

Methodology

Study design

A cross-sectional study was conducted using routine data recorded in medical files.

Study setting

Ethiopia is the second most populous nation on the African continent with an estimated population of 100 million [10]. It occupies a total area of 1,100,000 square kilometers. Leprosy prevention and control in Ethiopia

started in the 1950's. The country has five leprosy referral centers distributed across the country, including the Boru Meda Hospital, located in the central part of Ethiopia. The hospital was initially established in 1954 by missionaries, mainly to provide care for leprosy and related complications. Later on, the hospital started providing general medical services to the society in need. The hospital currently has 40 beds for leprosy and other dermatology cases. It also has three dermatology outpatient offices with two dermatologists: a tropical dermatology professional and a health officer with dermatology and leprosy training.

Leprosy case definitions and management

Leprosy management at the Boru Meda hospital follows the national guidelines. New cases were defined as patients who had never been treated for the disease and presented with active disease. We defined previously treated cases as patients with a documented history of leprosy who visited the hospital for care of complications and disability. Based on clinical and laboratory features, cases are diagnosed as pauci or multibacillary leprosy. Patients with one to five leprosy skin lesions and one nerve trunk enlargement are diagnosed as pauci-bacillary whereas multi-bacillary (MB) is diagnosed when patients present with six or more skin lesions, less than six skin lesions which have a positive slit skin smear result and if there is involvement (enlargement) of more than one nerve. Pauci-bacillary cases are treated with two drugs for 6 months while multibacillary ones are treated with three drugs for 12 months [11]. The leprosy disability management in the country is not well organized and unfortunately almost all hospitals in the country lack a dedicated disability prevention unit [9].

Study subject and period

Medical records of leprosy patients who visited the dermatology clinic of the Boru Meda hospital with a diagnosis of leprosy (both new and previously treated) from August 1st 2018 to December 1st 2018 were included in the study.

Study variables, Data collection and analysis

For each case, data were collected on socio-demographics, leprosy classification and clinical form, treatment provided, type of leprosy reactions, type and severity of leprosy related disabilities. Data were extracted from the medical records, which contain detailed evaluation of leprosy patients by dermatologists. Data were extracted by trained health officers using a standardized data extraction tool.

Descriptive analysis was done using calculation of medians (inter-quartile range (IQR)), frequencies and proportions. The data were presented using texts and statistical tables. Data storage and analysis was done using Epi-Data.

Ethical approval

Permission to conduct the study was obtained from Boru Meda Hospital management, Dessie, Ethiopia. Local ethics approval was received from Amhara Public Health institute, Bahir Dar, Ethiopia. The study was also approved by the Ethics Advisory Group of the International Union Against Tuberculosis and Lung Disease, Paris, France. As this was a record review study without patient identifiers, the issue of informed patient consent did not apply.

Results

Socio-demographic and other patient characteristics

Between August 1, 2018 and December 1, 2018 a total of 218 leprosy patient medical records were retrieved. With 10 files excluded due to missing key data, 208 were included in the analysis. Most patients ($n = 160$; 76.9%) were male. The median age was 44 years (IQR 32-57). There were 57 (27.4%) new cases and 151 (72.6%) previously treated cases. Ten of the new cases had a contact history with leprosy patients (Table 1).

WHO leprosy key elimination indicators amongst new cases

Thirty-four (59.6%) of the 57 new cases had grade 2 disability at diagnosis. The majority of newly diagnosed cases were MB ($n = 51$; 89.5%). There were 2 children diagnosed with leprosy (Table 2). Amongst new cases, 23 (40.4%) had ophthalmic involvement and 10 cases presented with vision impairment. Forty-four (77.2%) of the 57 new cases had neurologic

Table 1. Socio-demographic and clinical characteristics of leprosy cases at Boru Meda hospital in Amhara region, Ethiopia from august to December 2018.

Characteristic	Type of case	
	New (n=57) n (%)	Previously treated (n=151) n (%)
Median age, (IQR)	37 (28-50)	47 (33-60)
Sex		
Male	44 (77.2)	116 (76.8)
Female	13 (22.8)	35 (23.2)
Occupation		
Farmer	51 (89.5)	112 (74.2)
Unemployed	2 (3.5)	16 (10.6)
Merchant	0 (0.0)	14 (9.3)
Employed	4 (7.0)	7 (4.6)
Not recorded	0 (0.0)	2 (1.3)
Educational status		
No formal education	41 (71.9)	109 (72.2)
Primary	14 (24.6)	39 (25.8)
Secondary and above	2 (3.5)	3 (2)
Marital status		
Married	49 (86.0)	108 (71.5)
Single	7 (12.3)	22 (14.6)
Divorced and widowed	1 (1.8)	20 (13.2)
Contact history		
Yes	10 (17.5)	35 (23.2)
No	47 (82.5)	116 (76.8)
Family member with leprosy		
Yes	8 (14.0)	33 (21.9)
No	49 (86.0)	118 (78.1)
Comorbidities		
Diabetes mellitus	0 (0)	5 (3.3)
Hypertension	3 (5.3)	11 (7.3)
HIV	2 (3.5)	2 (1.3)

HIV: human immunodeficiency virus.

Table 2. World Health Organization key indicators amongst new leprosy cases in Boru Meda hospital, Amhara region, Ethiopia from August to December 2018.

	New cases (n = 57)		Previously treated cases (n = 151)	
	n	%	n	%
Disability grade				
Grade 0	21	36.8	47	31.1
Grade 1	2	3.5	7	4.6
Grade 2	34	59.6	97	64.2
WHO Type				
MB	51	89.5	141	93.4
PB	6	10.5	10	6.6
Age (in years)				
< 15	2	3.5	2	1.3

MB: Multi bacillary; PB: Pauci bacillary.

involvement. Sixteen cases (28%) presented with leprosy reactions (Table 3).

Complications amongst previously treated cases

Of the 151 previously treated cases seen during the study period, 104 (68.9%) presented with disabilities, predominantly grade two (n = 97; 64.2%). Neurological (n=130; 86.1%) and ophthalmic (n=97; 64.2%) complications were commonly reported. Moreover, self-amputation was reported in 42 (27.8%) patients.

Ninety two (61%) cases had experienced leprosy reactions (Table 3).

Discussion

Twenty years after the leprosy elimination target was declared in the country [9], this hospital based study using WHO target indicators showed that there is still evidence of disease transmission and delayed diagnosis. New leprosy cases were diagnosed in children, multibacillary disease was common and up to six in ten had severe disabilities at diagnosis. The study

Table 3. Complication and clinical profile among leprosy cases at Boru Meda hospital in Amhara region, Ethiopia from august to December 2018.

Type of complication	New cases (n=57)		Previously treated cases (n=151)	
	n	%	n	%
Self-amputation				
Yes	3	5.3	42	27.8
No	54	94.7	109	72.2
Orthopedic self-amputation				
Hand self-amputation	0	0	7	16.7
Feet self-amputation	0	0	14	33.3
Both hand and feet self-amputation	3	100	21	50
Ophthalmic complications				
Yes	23	40.4	97	64.2
No	34	59.6	54	35.8
Type of ophthalmic complications (multiple answer is possible)				
Red eye	11	47.8	41	42.3
Eye pain	7	30.4	43	44.3
Vision impairment	10	43.5	53	54.6
Exposure keratitis	5	21.7	19	19.6
Lagophthalmos	5	21.7	15	15.5
Neurologic complications (multiple answer is possible)				
Yes	44	77.2	130	86.1
No	13	22.8	21	13.9
Type of neurologic complications				
Neuropathic pain and/or ulcer	12	27.3	81	62.3
Paralysis and /or sensory impairment	39	88.6	71	54.6
Leprosy reactions				
No reaction	41	71.9	59	39.0
Type 1	12	21.1	67	44.4
Type 2	4	7	25	16.6

was done in one of the historically known hospitals for leprosy care, with health personnel experienced in leprosy diagnosis and care.

With national and international guidelines aiming for zero new cases in children by 2020, our findings are concerning. Guidelines recommend that for every child diagnosed with leprosy, a critical incident investigation should be done using standardized data collection tools [2]. Such an investigation was not done in our case, and the reasons behind should be assessed.

The proportion of multibacillary cases did not show any improvement relative to the national estimate in 2015 [9]. With a national target of less than 1% of grade two disabilities by 2020, the 59.6% prevalence in our study indicates delayed diagnosis. Community based studies recommended better quantify the extent of the problem, understand the reasons behind these delays and provide ways forward are highly needed. Besides limited community awareness, financial barriers could also exist, as leprosy diagnosis remains relatively centralized and some patients had to travel up to 200 km to get diagnosed. Stigma has also been found to prevail in many countries, contributing to diagnostic delays [12,13].

Several options to strengthen and decentralize leprosy case detection should be explored. Health extension workers could play a role in awareness raising, case detection and referral. This is currently not implemented in our setting. They could additionally be involved in contact tracing, a critical component of leprosy control programs that is often not or only partially operational [14]. Training of health care workers at the health center level and decentralization of diagnostic services could also improve case detection.

This study also revealed a high disability burden among leprosy patients after completion of treatment, indicating a currently unmet need of care. Many patients were suffering from different forms of neurologic and ophthalmic complications including vision loss and neuropathic ulcer. While rehabilitation programs currently exist to some extent in few hospitals in Ethiopia; multi-disciplinary care provision is needed to address the complex and diverse physical and psychosocial problems these patients face. Services should include physiotherapy, reconstructive surgery, pain management, foot care educational activities and psychosocial support.

This study has several strengths. The 2016-2020 national strategy spelt out the need for operational research to document progress [9], and our study provides a mid-term assessment from one of the five

leprosy hospitals. Based on the revised national guidelines, data recording had been enhanced at the hospital, leading to overall good quality data. There are also important limitations. As a health-facility based study, our findings do not reflect the case load within the community. It nevertheless indicates where we stand on the path to zero transmission and zero disability. The study is also confined to a limited geographical setting and was conducted over a short period. We call for larger studies across the country, complemented with community-based surveys.

Conclusion and recommendation

This study shows evidence of ongoing leprosy transmission and delayed diagnosis in the country. This calls for operational research to determine the underlying reasons and provide ways forward for the national program. At the same time, the high burden of disabilities in previously treated cases should be addressed.

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