

## Major Article

# Hansen's disease deformities in a high risk area in Mozambique: A case study

Abdoulaye Marega<sup>[1]</sup>, Paulo das Neves Pires<sup>[1]</sup>, Jaibo Mucifo<sup>[1]</sup> and Artur Muloliwa<sup>[2]</sup>

[1]. Faculty of Health Sciences, Lúrio University, Nampula, Mozambique.  
[2]. Nampula Provincial Health Directorate, Ministry of Health, Nampula, Mozambique.

### Abstract

**Introduction:** Hansen's disease is no longer a public health problem in Mozambique, since 2008 (incidence under 1 / 10,000 inhabitants). The country is one of the most affected in the world and Nampula province's Murrupula district (incidence 1.7 / 10,000) has a high deformity rate (22% in 2010). This study aimed to identify high deformity rate associated determinants and proposals for better health program results. **Methods:** This study involved a descriptive quantitative survey, systematic observation of patients and health professionals, and a survey of community volunteers. Data were analyzed using *Epi Info* 7.2. Pearson's chi-square and Fisher's exact test were used to assess statistical association with deformity, with a significance level of 5% and 95% confidence interval. Ethical procedures followed the Helsinki declaration (2013). **Results:** Among 238 subjects, 175 were patients and 63 leprosy health staff. Most patients relied on subsistence agriculture facing social exclusion (43, 25%). The waiting time from first symptoms to diagnosis was over one year for 63%. Deformity affected 116 subjects (68%), particularly those who considered the disease as God's desire ( $p = 0.01$ ), and practiced traditional treatments ( $p = 0.001$ ). Among leprosy health staff, 35 (52%) were not trained on diagnosis and management. **Conclusions:** High deformity rate is associated with low economic status, the belief that the disease is God's desire, the use of traditional healers, late diagnosis, and poor disease management. A health education program targeting professionals and population, with infection screening and self-care groups can prevent deformities.

**Keywords:** Deformity. Hansen's disease. Leprosy. Nampula. Mozambique.

### INTRODUCTION

Leprosy (Hansen's disease) has been a health problem since ancient times. It is a chronic granulomatous infection caused by *Mycobacterium leprae* (Hansen bacillus, discovered in 1940, an intracellular acid-fast rod) and a zoonosis (animal reservoirs are the pangolin and non-human primates). It affects superficial tissues, especially the skin, peripheral nerves and nasal mucosa (due to the agent's tropism for lower temperature areas)<sup>1-3</sup>.

Leprosy is often a family infection with an incubation period of three to five years. Targeting peripheral nerves, it has high incapacitating potential causing deformities, mutilations and physical disability. The disease can affect patients' physical

appearance, causing hopelessness, feelings of rejection, stigma, and discrimination<sup>4</sup>.

Leprosy incidence worldwide diminished from 265,661 new cases in 2005 to 210,758 in 2015, with 1,335 in Mozambique<sup>5</sup>.

Mozambique had the highest prevalence of leprosy in Africa in 2007 (1.4 / 10,000 inhabitants) and was one of the countries most affected by the disease worldwide. The Mozambican epidemiological situation is heterogeneous, with wide prevalence variation among regions (Nampula Provincial Health Directorate [NPHD]: research proposal, 2013). Hansen's disease is a public health problem in Nampula province (one of the highest prevalence rates, 2.1 / 10,000, with a detection rate of 5.2 / 100,000), Murrupula district (1.7 / 10,000), with a high deformity rate among new cases (NPHD provincial report, 2013).

Asymptomatic carriers could explain the transmissibility of the disease and screening household contacts would be useful to control this infection<sup>6</sup>. The disease affects mainly poor families. Similarly, in India, the world's largest contributor to the disease

**Corresponding author:** Paulo das Neves Pires.

**e-mail:** druidatom@gmail.com

**Orcid:** 0000-0002-2586-9955

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incidence, the spread of leprosy is causing deformities in impoverished areas dispersed throughout the country.

Deformities and disabilities due to leprosy are preventable, but in Mozambique this situation is distressing. In Nampula, according to the 2010 Leprosy National Program (LNP) Report, the deformity rate in Murrupula was at 12% and 22% in 2009 and 2010, respectively.

The Mozambican Government launched a social campaign to prevent deformities and implemented a rehabilitation program (PRID), to reduce disease impact. Community-based rehabilitation groups were created, aiming to improve living conditions<sup>7,8</sup>.

However, Nampula keeps reporting new cases of deformities, particularly in Murrupula. A 2008 NPHD study revealed 493 new cases in the first half of 2007, 9.7% with deformity grade two. A patient's total degree of disability is determined by adding degrees given to each eye, hand and foot, being proportional to the severity of the disease<sup>9</sup>.

Facing these challenges, the LNP in Nampula province is aiming to reduce deformities and disabilities caused by leprosy among new patients, by studying its causes and setting up self-care groups.

**General:** This study aimed to identify factors contributing to the high deformity rate among leprosy patients in Murrupula and propose management measures to improve patients' health and productivity.

#### Specific:

- Describe patients affected by leprosy in Murrupula between 2006 and 2013.
- Characterize deformity cases.
- Analyze solutions by leprosy management staff.
- Produce recommendations to reduce the deformity rate.

## METHODS

In this descriptive study, quantitative with documentary and desk review, we applied a survey and systematic observation to patients, and surveys with those involved in LNP treatment and management.

#### Target groups:

- Patients diagnosed between 2006 and 2013 with leprosy.
- LNP staff: health professionals, district health department representatives, district administrator, traditional leaders, and self-care volunteers.

The study period corresponds to the launching of self-care groups, when the district should be organized in structural and functional terms for PRID. Murrupula district has a population of 170,072 inhabitants (2013) concentrated in five main villages (Headquarters, Nihessiue, Chinga, Cazuzo, and Namitotelane). The study covered people from all villages, including members of the four self-care groups and the district's LNP network.

The study population (238) was set according to the universe of leprosy patients and people working with LNP living in Murrupula:

- 175 people affected by Hansen's disease.
- 63 LPN staff members.

Data collection used survey models set according to target groups. A team of nine local data collectors, fluent in Macua (local language) and Portuguese (the official language in Mozambique), were trained and equipped with respective surveys. To validate data collection tools and study feasibility, a survey pilot test was conducted at the district headquarters and Naache locality, with subjects other than study participants.

Data were introduced, treated and analyzed using *Epi Info* 7.2, with a double check for quality control. Pearson's chi-square and Fisher's exact test were used to assess the association among identified factors and deformity rates, with a significance level of 5% and 95% confidence interval (CI).

### Ethical considerations

The research protocol was approved by Lúrio University's Institutional Committee for Health Bioethics. It included the principal researcher's commitment statement and ethical statements as well as absence of conflicts of interest declarations from all researchers. Before the surveys, an informed consent form was presented to each participant, in simple language, and was signed after being explained and understood. All patients with acute illness were referred and transported to the nearest health care facility. This study followed all the tenets of the Helsinki Declaration (2013).

## RESULTS

### Patients

In 175 patients living in 12 localities, we observed 171, four abandoned after the survey; 68% (116) showed low sensibility and deformities (degree one, 51, 30%; degree two, 65, 38%), 32% (degree zero, 55) without detectable lesions. **Table 1** details the sample characteristics.

Most patients lived in Murrupula town, Nihessiue and Namitotelane. We found three children (2%) and six adolescents (3%) with the disease. Mostly, deformities affected the nose, foot and hand.

The principal patients' concepts about the disease, its consequences and treatment are presented in **Table 2**. Standard leprosy complete treatment duration varied according to disease level, 12 months with lepromatous leprosy and six months with tuberculoid leprosy.

We verified a high leprosy deformity incidence in 2007 and 2009 (respectively 40% and 56%), less in 2010 and 2012 (25% and 14%) and increasing again in 2013 (35%).

We found a statistically significant association between the presence of deformity and the concept of the disease's cause as God's desire or "destiny" ( $p = 0.04$ ).

Traditional healers treated 26% of patients and 66% of those presented deformity, showing that the use of traditional healers is significantly associated with deformity (OR = 0.2, 95% CI: 0.0 – 0.5;  $p = 0.0002$ ) (**Table 3**).

Analyzing body deformity distribution showed 48% of patients with three or more affected organs, 33% with one and 19% with two. The most affected organ was the nose (28 patients, 44%) followed by the foot (20, 32%) and hand (15, 24%).

**TABLE 1:** Leprosy patients' demographic, social and economic characteristics.

Variable (survey number) *	Characteristic	n	%
Gender (n = 173)	Female	89	51
	Male	84	49
Age (n = 173)	Adults (> 25 years)	152	88
Residence (n = 175)	Murrupula (Umuato, Umpuata, Tucua)	73	47
	Nihessiue (Lupo, Naha, Lepa, Mulhanian),	47	26
	Namitotelane (Nacocolo, Namiope, Namicope)	44	25
	Other districts (Alto Ligonha, Mogovolas)	8	2
Education (n = 173)	Completed primary education	101	58
	Did not attend school	51	35
Marital status (n = 173)	Married or "living together"	87	50
	Single, divorced or widow	86	50
Religion (n = 172)	Islamism	77	45
	Christian	54	32
	No religion	32	18
	Animism	9	5
Occupation (n = 173)	Small farmer (subsistence agriculture),	150	87
	Do not have	122	71
Additional income (n = 173)	Family support	33	19
	Public subsidy	9	5
Food availability (n = 174)	Facing food scarcity	96	55
Average daily meals number (n = 172)	Two meals per day	127	74
	One meal per day	31	18
	Three meals per day	14	8
Health care access (n = 173)	Do not have any means of transportation	151	87
	Have a bicycle	19	11

\*Surveyed subjects number variation follows survey validated responses; n: subjects number; %: percentage of total surveyed subjects.

Evaluating total deformity grade in each patient (62) we found 42% with grade 4, 32% with grade 2 and 26% with grade 6 (3 affected organs: hand, foot and eye, excluding the nose).

Sight problems occurred in 39% of patients with deformity and none of those without deformity. Among 170 patients, 7% felt discriminated (by family or neighbors) and 18% auto-excluded.

Considering treatment duration, 65% of patients had between 7 and 12 months (multibacillary leprosy), 34% between 1 and 6 months (paucibacillary leprosy) and 2% more than 12 months. The study contributed to diagnosing 14 new leprosy cases detected during data collection, referred and transported to Murrupula Health Centre.

### Leprosy National Program staff

The 63 subjects were mostly men (39, 62%) between 25 to 44 years old (58%) and between 25 to 29 years (24%); 19 (30%) are illiterate and 34 (54%) had completed primary school. Regarding their function, 32 (51%) were community volunteers and 13 (21%) community leaders. The majority, 40 (63%) practiced subsistence agriculture as their main activity.

Most of them, 45 (71%), traveled on foot and 13 (21%) had a bicycle. Among them 32 (51%) had between one and five years of working experience with the LNP, 12 (19%) between 11 and 15 years and 6 (10%) with 6 to 10 years; 33 (52%) had no specific training on the disease, 11 (17%) had one training session and 9 (14%) two. In this group, 8 subjects (13%) had

**TABLE 2:** Patients' concepts about leprosy disease and treatment.

Variable (survey number) *	Characteristic	n	%
Cause of leprosy (n = 171)	God's desire / "destiny" <sup>(1)</sup>	99	58
	Common disease	37	22
	Genetic inheritance (intra-family transmission).	25	15
Treatment (n = 172)	Is curable	168	98
	Looks for treatment in HU	164	95
Distance to the health unit (n = 172)	Less than 10 km	104	61
	More than 11 km	68	40
Discrimination and stigma (n = 175)	Do not feel stigma	144	82
	Feels stigmatized	31	18
	Feels being discriminated	12	7
Deformities (n = 171)	Frequency (Grade 1 and 2)	116	68
	Diagnosis year 2006	74	43
	Diagnosis year 2007	27	16
Waiting time between diagnosis and treatment (n = 173).	12 months after diagnosis	146	86
	Patients who initiated treatment 12 months after diagnosis without deformity	92	63
	Patients who initiated treatment 12 months after diagnosis with deformity	54	37
Treatment duration (n = 173)	7 to 12 months	116	67
	One to six months	57	33
Traditional healers (n = 175)	Use traditional healers to treat the disease	28	24
	Deformity rate in those that use traditional healers to treat the disease	23	82

\* Surveyed subjects number variation follows survey validated responses; n: subjects number; %: percentage of total surveyed subjects; <sup>(1)</sup>: leprosy infection is believed to be pre-determinate by God.

been affected by leprosy and 75% had observed deformities in their patients.

The LNP staff's concepts about the disease, its consequences, treatment and management are presented in **Table 4**.

To better disease management, LNP staff suggested several proposals pointing two statistically significant propositions: training health staff and volunteers on leprosy diagnosis and treatment ( $p=0.03$ ) and providing communication access among volunteers, patients and leprosy program managers ( $p=0.02$ ). **Table 5** presents mostly mentioned propositions.

## DISCUSSION

The leprosy incidence in Murrupula district might be increasing in three localities and we found new cases in children and adolescents. The high occurrence of deformity among leprosy patients reveals the persistence of the problem in these communities.

The disease affects mainly people with low-income, illiterate, relying on subsistence agriculture, and facing food scarcity. Patients' social isolation (absence of a partner), stigma and discrimination, income unavailability, lack of food, and

low literacy, all contributed to increasing the probability of deformities. Even though most patients completed primary school, the surveys were taken in Macua due to the limited facility with the Portuguese language. The language difficulties also limited the effectiveness of attempts to educate patients about leprosy. The same was shown in a Brazilian study, where the highest number of leprosy patients, especially with incapacitating lesions, had a low socioeconomic profile<sup>10</sup>.

Many patients said they did not practice any religion, which might explain their social exclusion in the community. In African societies, especially rural settings, religious practice is usually the primary mean of socialization; hence it is rare to find someone without faith. The fact that 10% declared themselves animists might also contribute to social exclusion since it is rejected by both Christianity and Islam.

Regarding patient's perception about the disease and the degree of deformity, our findings show a statistically significant association between those who perceive it as a desire of God or destiny, as opposed to those who perceive it as a common disease ( $p = 0,01$ ).

**TABLE 3:** Leprosy deformity rate per year, sample's social characteristics and treatment.

Characteristic	Total		Deformity		No deformity		p
	n		n	%	n	%	
<b>Year of Diagnosis</b>							
2006	72		29	40.3	43	59.7	0.4
2007	27		13	48.1	14	51.9	
2008	13		4	30.8	9	69.2	
2009	9		5	55.6	4	44.4	
2010	8		2	25.0	6	75.0	
2011	10		3	30.0	7	70.0	
2012	14		2	14.3	12	85.7	
2013	17		6	35.3	11	64.7	
<b>Discrimination</b>							
No	158		58	36.7	100	63.3	0.5
Yes	12		6	50.0	6	50.0	
<b>Stigma</b>							
Yes	31		14	45.2	17	54.8	0.4
No	139		50	36.0	89	64.0	
<b>Treatment (N=169)</b>							
0- 6 months	57		15	26.3	42	73.7	0.08
7 - 12 months	109		47	43.1	62	56.9	
More than 12 months	3		2	66.7	1	33.3	
<b>Waiting time before treatment</b>							
12 months	146		54	37.0	92	63.0	0.9
More than 12 months	23		9	39.1	14	60.9	
<b>Traditional healers</b>							
Not users	135		41	30.4	94	69.6	
Users	35		23	65.7	12	34.3	0.0002*
<b>Sight problems</b>							
Yes	25		25	100.0	0	0.0	0.001*
No	145		39	26.9	106	73.1	
<b>Leprosy concept (N=169)</b>							
God's will (destiny)	98		40	40.8	58	59.2	0.04*
Common disease	36		11	30.6	25	69.4	
Inheritance	25		5	20.0	20	80.0	
Do not know	8		5	62.5	3	37.5	
Witchcraft	2		2	100.0	0	0.0	
<b>Total</b>	<b>170</b>		<b>64</b>	<b>37.6</b>	<b>106</b>	<b>62.4</b>	

N: subjects' number; n: subjects' number; %: percentage of total surveyed subjects; p: significance level; \* statistically significant.

**TABLE 4:** Leprosy National Program staff' concepts about the disease and its management

Variable (63 subjects)	Characteristic	N.	%
Leprosy causes <sup>1</sup>	God's desire / "destiny" <sup>2</sup>	38	60
	Common disease	14	22
	Genetic inheritance (intra-family transmission).	4	6
Discrimination and stigma	Patients feels stigmatized	28	44
	Patients are socially excluded	22	35
	Patients are abandoned by families	12	19
	Patients are desperate	7	11
Number of domiciliary visits to each of their patients	3	23	37
	2	21	33
	1	12	19
Treatment interruptions	Staff responsibility	22	35
	Tablets stock rupture at health center	15	21
	Patient forgot taking medication	7	11

N.: subjects' number; %: percentage of total surveyed subjects; <sup>(1)</sup>: leprosy national program' volunteers and community leaders' opinions on leprosy causes; <sup>(2)</sup>: leprosy infection is believed to be pre-determinate by God.

**TABLE 5:** Leprosy National Program staff's proposals for better leprosy management.

Proposals <sup>(1)</sup>	n	%
Leprosy education program for communities in target villages	51	81
Health staff training on leprosy early diagnosis and deformity risk identification	46	73
Produce and distribute information and educational materials		
Transport means for volunteers	43	68
Regular training for community health volunteers		
Implementation of economically sustainable initiatives for patients	39	62
Establishment of a social insertion center	33	52

<sup>(1)</sup>health professionals, community leaders and leprosy national program volunteers suggest activities to reduce leprosy incidence and deformity rate; **n**: subjects number; %: percentage of total surveyed subjects.

Similarly, most health volunteers have this concept of disease as punishment of God. We can relate this interpretation with local culture, in which leprosy is a "damned" disease, a victim of the wrath of supernatural beings (the spirits). Such views may cause delays in seeking care. These results corroborate other studies in Zambezi valley (Zambézia and Sofala provinces) and in Namaita (Nampula)<sup>11</sup>.

Furthermore, we found a statistically significant association between the use of traditional healers and deformity degree ( $p = 0.001$ ). The Namaita study reveals that leprosy patients practiced traditional healing regularly. The complexity of the "evil world" in Africa, explains the frequency and diversity of traditional healers who, in *Macua* society, intervene in disease treatment<sup>12</sup>.

The LNP staff also showed low literacy, economic status and leprosy training. Another study in Brazil showed that late diagnoses in most individuals was due to the population's lack of information about leprosy symptoms, health professionals' poor training, the insidious evolution of the disease, leading many of them to physical disabilities<sup>13</sup>.

Concerning factors contributing to the persistence of Hansen's disease, we found a long period between diagnosis and treatment, failure in patients follow up and low adherence to treatment. Other studies in Brazil confirm our results: deficient health care organization, failure to avoid dropouts, no explanation about the severity of the disease, stigmatizing the patient. To deal with this situation it is necessary to decentralize

leprosy care, an important strategy to eliminate the disease<sup>14</sup>. To achieve this, our leprosy program staff pointed information regarding the target community and education and training health staff and volunteers on leprosy diagnosis and treatment.

## CONCLUSION

Although Mozambique has removed leprosy from health programs priorities, the Murrupula population reveals a growing incidence with new cases in children and adolescents and a high deformity rate.

The affected population feels discriminated and they belong to a low socio-economic and literacy degree stratum. The high rate of deformities is associated with the concept of the disease as "God's desire, destiny and spirits," the practice of traditional healing and the delay in diagnosis by health professionals.

Despite the significant number of health professional training on leprosy diagnosis and treatment, frequent staff rotation prevented a consolidation of leprosy control in the district. As a result, patients with early signs and symptoms are not diagnosed and treatment is only started when they have mutilations.

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**Conflict of Interest:** The authors declare that there is no conflict of interest.

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