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BURDEN ASSESSMENT OF PODOCONIOSIS IN WAYU TUKA WOREDA, EAST WOLLEGA ZONE, WESTERN ETHIOPIA: A COMMUNITY BASED CROSS-SECTIONAL STUDY

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15 **BURDEN ASSESSMENT OF PODOCONIOSIS IN WAYU TUKA WOREDA, EAST**
16 **WOLLEGA ZONE, WESTERN ETHIOPIA: A COMMUNITY BASED CROSS-**
17 **SECTIONAL STUDY**
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Objective: Podoconiosis is a neglected tropical disease characterized by slowly progressive swelling of the foot and lower leg. It is prevalent among subsistence barefoot farmers who live and work in highland areas of the tropics. This study was conducted in Wayu Tuka *woreda* (district), western Ethiopia to determine the prevalence of podoconiosis and assess factors affecting acute lymphangioadenitis (ALA) episodes.

Methods and analysis: A two phase, community-based cross-sectional study was conducted between January and March 2015. First, all households in the district were surveyed to determine the prevalence of podoconiosis. This was followed by a second phase in which 366 people with podoconiosis from four randomly selected *kebeles* (sub districts) were assessed for clinical features of the disease, shoe-wearing habits, personal hygiene, social stigma and functional impairment. Data entered into Epi DATA were then exported to SPSS. Logistic regression analysis was conducted to identify factors associated with ALA.

Results: Prevalence of podoconiosis in the population was 3.05 % (1197/39256) (95% CI = 2.9% to 3.2%). The prevalence was significantly higher among women than men (3.67% vs. 2.4%). Most (92.2%) people with podoconiosis were in the economically active age group (15-64 years) in the first phase survey. Of participants in the second phase of the study, 43% had stage 2 disease and 38.1% had 'moss'-like skin changes. People with podoconiosis had on average 23.3 episodes of ALA/year and on average, each person with podoconiosis lost 149.5 days of activity/year. Never walking barefoot and daily foot washing were both associated with decreased odds of ALA (AOR=0.23; 95%CI: 0.06-0.80 and 0.09; 95%CI; 0.01-0.75, respectively).

Conclusion: A relatively high prevalence of podoconiosis, frequent ALA episodes and considerable decreases in daily activities were identified in this district. Footwear use and daily foot hygiene were associated with decreased odds of ALA. We recommend prevention and morbidity management interventions to address this developmental challenge.

Key words: Acute adenolymphangitis, Burden, Ethiopia, Podoconiosis

Strengths and Limitation of this study

- This was a two-phase study conducted in a district of western Ethiopia
- A complete census through house-to-house visits to identify all cases of podoconiosis was done
- To characterize people with podoconiosis, a second phase assessment (frequency of episodes of ALA, their association with variables such as age of the patient and clinical stage) was conducted among a subsample of patients
- The study provides a profile of people with podoconiosis in the district, which is important for rational deployment of limited resources towards prevention and treatment of the disease.
- A limitation of the study is case identification – this was not supported by serological tests to exclude lymphatic filariasis.
- A second limitation was that self-report of ALA was not validated in any way.

Background

Podoconiosis is a disabling and stigmatizing neglected tropical disease (NTD), which affects the lower limb. It is caused by longstanding exposure to red clay soil of volcanic origin[1]. It is characterized by the development of persistent swelling of the foot which progresses to the dorsum and gradually extends up the lower leg. Podoconiosis affects the lower limbs, and the swelling is usually limited to below the knees[2,3].

Podoconiosis can be distinguished from filarial elephantiasis through history and clinical examination: podoconiosis develops first in the foot, it causes bilateral but asymmetric swelling often confined to the lower leg, and groin involvement is rare in podoconiosis. In contrast, the swelling of lymphatic filariasis is commonly found above the knee and often involves the groin. Another common differential diagnosis is leprosy lymphoedema, but podoconiosis can be distinguished from this because sensation persists in the toes and forefoot, and trophic ulcers, thickened nerves and hand involvement are not found[4,5].

Acute adenolymphangitis (ALA) is a common and disabling complication of podoconiosis lymphoedema, yet has been very little investigated to date. According to studies conducted in northern and western Ethiopia, podoconiosis patients experienced on average five episodes of ALA per year and up to 90 days per year incapacitated by ALA [6, 7]. In filarial lymphoedema (LF), episodes of ALA have been shown to accelerate damage to peripheral lymphatic vessels and to lead to fibrosis [8].

Prevalence of podoconiosis is high in many highland parts of Africa: Cameroon [9], Rwanda [10], Ethiopia [11]. In Ethiopia, prevalence of podoconiosis is about 5% in areas with irritant soil [1], eleven million Ethiopians (18% of the population) are at risk through exposure to the irritant soil [1] and up to 90% of affected individuals are from the most economically active age groups [6]. In a study in southern Ethiopia, it was found that affected individuals lose 45% of their total productive work days. Direct and productivity cost of podoconiosis in a group of 1.5million inhabitants have been estimated at US\$16million a year, imposing an economic burden of \$208million per year in Ethiopia [12].

Recently, podoconiosis and other Neglected Tropical Diseases(NTDs) have been receiving attention in Ethiopia[13]. The Federal Ministry of Health of Ethiopia (FMOH) endorsed inclusion of podoconiosis in the National Master Plan for Neglected Tropical Diseases in 2011, and nationwide mapping of podoconiosis and lymphatic filariasis was conducted in 2013[13-15]. While *woreda*-level burden of disease as manifested by leg swelling has been described in several recent studies [6,7,16], very little attention has been given to acute

adenolymphadenitis (ALA), another important sequela of podoconiosis. This study aimed to determine the burden of both podoconiosis lymphoedema and ALA in western Ethiopia.

Methods

Study Area and Period

The study was conducted in Wayu Tuka *woreda* (an equivalent of a district in Ethiopia), in East Wollega Zone, Oromia Region, western Ethiopia. It is located 324Km from the capital Addis Ababa, has an altitude of 1700-2,200 metres above sea level and an average annual rainfall of 2,400mm. The population of Wayu Tuka *woreda* is estimated at 75,970, living in 15,930 households [17], of which 95% are in rural areas and depend on subsistence farming for their living. This study was conducted from January-March, 2015.

Study Design and Sampling

A two phase cross-sectional community based study was conducted. In the first phase, all the households in the *woreda* were surveyed to determine the prevalence of podoconiosis and to identify peoples with podoconiosis for the second phase study. In the second phase, 366 people with podoconiosis from four randomly selected *kebeles* (an aggregate of villages and the smallest administrative unit in Ethiopia) were approached to assess clinical features of the disease, habits of shoe-wearing, personal hygiene, social stigma due to the disease and functional impairment.

Inclusion and Exclusion Criteria

All individuals who were willing to participate were included, however, in the second phase; people with podoconiosis with mental health problems precluding them answering questions with substantial recall were excluded.

Data Collection

Thirty Level 4-holder nurses employed as Health Extension Workers and two Bachelor of Science (BSc) nurse supervisors were recruited in the first phase survey, while ten Health Extension Workers and two BSc nurse supervisors were recruited for the second phase survey. The Health Extension Workers were responsible for house-to-house enumeration of podoconiosis cases and the interviewing and physical examination of people with podoconiosis). All field staffs were trained for one day before carrying out data collection. The training consisted of techniques and approaches for obtaining informed consent from participants, interviewing techniques, podoconiosis diagnostic features, clinical staging according to a standard method, assessment of ALA, measurement of leg circumference, assessment of presence of open wounds, and features that differentiate lymphoedema and leg swelling resulting from podoconiosis from other diseases such as leprosy and lymphatic filariasis. The nurses were responsible for supervising the activities of the Health Extension Workers. In households where

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there was more than one person with podoconiosis, all of them were invited to interview and physical examination including measurement of leg circumference.

Data Collection Tools

An interviewer-administered questionnaire was used to collect data. The questionnaire was prepared in English, translated into Afaan Oromo (local language) and translated back to English to maintain consistency of the variables under question. A measuring tape was used to measure the greatest below-knee circumference of the legs of people with podoconiosis.

Operational Definitions

Acute Adenolymphangitis (ALA): A reddish, hot, swollen leg with a painful groin [6,18].

Chagino: the time around the new moon, often associated in local understanding with weather changes (6).

Economically active age: Any one between the ages of 15-65[12].

Leg circumference: The largest circumference between the level of the ankle and the knee measured using a tape, to a precision level of the nearest centimetre[19].

Mossy lesions: Papillomatous horny lesions giving the skin a rough appearance.

A person with podoconiosis: An individual in an endemic area diagnosed by a trained nurse and a health extension worker who fulfils all of the following diagnostic criteria: history of burning sensation in the feet when the swelling started; visible swelling that started at the feet and progressed upwards; with at least stage one of the five clinical stages of podoconiosis; and with no known clinical signs or symptoms of leprosy or lymphatic filariasis [4].

Data Processing and Analysis

Data were entered into Epi DATA then exported to SPSS data version 20 and summarized in tables. To identify risk factors associated with ALA, a bivariate logistic regression was performed, and then multivariable logistic regression was conducted. A significance level of 0.05 was used as a cut-off.

Ethical Considerations

Ethical clearance was obtained from Wollega University Ethical Review Committee. After discussing the study with the local authorities we obtained written approval to conduct the study in all *kebeles*. The ultimate purpose of the study was explained and data were collected only from those who gave written consent. The participants were informed of their rights including ability to stop participating at any time or to skip questions they do not wish to respond to. For individuals less than 18 years of age, consent was obtained from parents or guardians. People with podoconiosis were advised to attend health clinics for management of the condition.

RESULTS

Socio-Demographic Characteristics of People with Podoconiosis in Phase 1 Survey

The male to female ratio was 1:1.58. The mean (\pm SD) age of people with podoconiosis was 43.1 \pm 13.26 years. Slightly more than nine in ten (1,117, 93.3%) belonged to the economically active age group. The majority (95%) lived in rural areas and was reliant on subsistence farming. Slightly more than half (653, 53.9%) of households had a family size of less than four, and the average family size was 4.43 \pm 2.06 (with a range of 1-15, Table 1).

Table 1 Socio demographic characteristics of people with podoconiosis in the phase 1 survey, Wayu Tuka *Woreda*, January to March 2015 (N = 1,197).

Characteristics	Category	N (%)
Marital Status	Single	131 (10.9%)
	Married	905 (75.6)
	Divorced	25 (2.1)
	Widowed	136 (11.4)
Family Size	1-4	653 (53.9)
	\geq 5	559 (46.1)

Burden of Podoconiosis

Prevalence of podoconiosis in the population was 3.05%(1197/39256) (95% CI = 2.9% to 3.2%). The prevalence was significantly higher among women than men (3.67 % vs.2.40 %).Prevalence disaggregated by age and sex is shown in Table 2.

Table 2. Prevalence of podoconiosis disaggregated by age and sex in Wayu Tuka *Woreda*

Age	Male			Female		
	Number examined	People with podoconiosis	Prevalence (%)	Number examined	People with podoconiosis	Prevalence (%)
15-24	8025	10	0.1	8801	9	0.1
25-34	4574	33	0.7	4516	83	1.8
35-44	3059	110	3.6	2888	199	6.9
45-54	1668	137	8.2	1765	199	11.3
55-64	1020	80	7.8	1064	148	13.9
65 ⁺	942	94	10.0	935	95	10.2
Total	19288	464	2.4	19968	733	3.7

Socio-Demographic Characteristics of People with Podoconiosis in the Phase 2 Study

A total of 366 people with podoconiosis were approached for the detailed study in four randomly selected *kebeles*. These participants consisted of 134 (36.6%) males and 232 (63.4%) females. On average, the respondents had lived in the study area for 38.64 \pm 18.24 years. Slightly more than nine in ten, 337 (92%), of the respondents belonged to the economically active age group.

More than 75% had no formal education, and the majority (346, 94.5%) of the study participants were farmers (Table 3).

Table 3: Socio Demographic characteristics of people with podoconiosis in the phase 2 study, Wayu Tuka *Woreda*, January to March, 2015(n = 366).

Characteristics	Category	N (%)
Sex	Male	134 (36.6)
	Female	232 (63.4)
Age	15-24	25 (6.8)
	25-34	54 (14.8)
	35-44	88 (24)
	45-54	87 (23.7)
	55-64	67 (18.3)
	65 ⁺	45 (12.3)
Educational Status	Cannot read or write	279(76.2)
	Can read and write	87(23.8)
Occupation	Farming	346(94.5)
	Others ¹	20(5.5)
Marital Status	Single	81(22.1)
	Married	208(56.8)
	Others ²	77(21.0)

¹Others¹ = begging, students, retired, Others²=widowed, divorced, separated

Clinical Characterization of Podoconiosis in Phase 2 Study.

People with podoconiosis in the four randomly selected *kebeles* were categorized into five clinical stages according to pre-existing clinical staging criteria [19]. The majority had stage two or stage three disease (159, 43.4%, and 115, 31.4%, respectively). The greatest below-knee leg circumference was 26.6 ± 5.3 cm (range 18-45). Table 4 summarizes clinical characteristics of podoconiosis.

Table 4. Clinical characterization of people with podoconiosis in phase 2 study, Wayu Tuka *Woreda*, January to March, 2015.

Characteristics	Category	N (%)
Clinical Stage (n=366)	One	2 (0.5)
	Two	159 (43.4)

	Three	115 (31.4)
	Four	66 (18.)
	Five	24 (6.6)
Mossy Appearance (n=366)	Yes	141 (38.5)
	No	225 (61.5)
Wound (n=366)	Yes	138 (37.7)
	No	228 (62.3)
Leg Circumference (Cm, n=359)	18-27	220 (61.3)
	28-36	123 (34.3)
	37-45	16 (4.5)

Features of ALA

ALA is the major cause of morbidity in people with podoconiosis. The majority, (325, 88.8%), of people with podoconiosis had experienced ALA in the year before the survey. The most recent episode of ALA had occurred an average of 2.97 weeks before the study. On average, people with podoconiosis experienced 23.3±14.4 ALA episodes/year, and on average, were bed bound for 6.42± 5.39 days; meaning that on average, each person with podoconiosis lost 149.5 days of activity per year. Nearly half (182, 49.8%) of the people with podoconiosis had ALA at the time the interview was conducted. More than one-third (38.4%) of people with podoconiosis reported that ALA episodes were worse during the rainy season. The major trigger of an ALA episode was prolonged walking (reported by 163, 44.1%). Many (137, 42.2%) had retired to bed without treatment at least once in the past year as a coping mechanism to ALA trigger. During episodes of ALA, 40% of people with podoconiosis had sought treatment at a podoconiosis treatment clinic while 9.5% had not sought treatment of any kind (Table 5).

Table 5. Features of ALA among people with podoconiosis in Wayu Tuka *Woreda*, January -March 2015

Characteristics	Category	N (%)
ALA in year before survey (n=366)	Yes	325 (88.8)
	No	41 (11.2)
ALA at time of Interview (n=366)	Yes	182 (49.8)
	No	184 (50.2)
Time when ALA worsen (n=325)	Rainy season	142 (38.4)
	All the time	74 (32.1)

	During “Chagino”	68 (18.4)
	Hot and dry season	41 (11.1)
Triggers of acute attack (n=325)	Long walk	163 (44.1)
	Hard physical work	66 (17.8)
	Walking barefoot	64 (17.3)
	More work than usual	32 (8.6)
ALA coping mechanisms (n=325)	Stay in bed	137 (42.2)
	Resort to less physical work	120 (36.9)
	Get treatment	68 (20.9)
Place treated (n=366)	Podoconiosis treatment centre	148 (40.4)
	Health Facilities*	93 (25.4)
	Traditional	90 (24.5)
	Treatment not sought	35 (9.5)

*NB. Health Facilities = Health Center, Health Post, Hospital and Pharmacy/drug store

Factors Associated with ALA

In multivariate analysis, never walking barefoot and daily foot washing was associated with lower odds of ALA. People with podoconiosis who never walked barefoot had one quarter the odds of ALA than those who walked barefoot at times [AOR=0.23, 95% CI 0.06-0.80, p=0.025]. People with podoconiosis who washed their feet daily had one twelfth the odds of ALA of those who did not [AOR=0.09, 95% CI 0.01-0.75, p = 0.023]. Variables such as patient’s age, clinical stage of disease, mossy appearance, and presence of wound were associated in the bivariate analysis but these associations did not persist after multiple logistic regressions (Table 6).

Table 6: Factors associated with ALA in people with podoconiosis Wayu Tuka *Woreda*, January - March 2015

Variable	ALA		COR (95%CI)	AOR (95%CI)	P-value	
	Yes (%)	No (%)				
Situations in which people with podoconiosis walk barefoot						
Farming	Y*	83 (22.7)	242 (66)	1.14 (0.54-2.29)	1.46 (0.6-3.6)	0.403
	N [†]	17 (4.6)	24 (6.5)	1	1	
Non-Farming	Y	74 (20)	251 (68.5)	0.56 (0.24-1.3)	0.39 (0.14-1.05)	0.063
	N	34 (9.2)	20 (5.4)	1	1	
Home	Y	78 (21.3)	247 (67.5)	1.84 (0.86-3.94)	1.48 (0.49-4.1)	0.384

	N	20 (5.5)	21 (5.7)	1	1	1
Always	Y	26 (7.01)	299 (81.7)	0.49 (0.09-2.49)	0.41 (0.06-2.54)	0.335
barefooted	N	2 (0.54)	39 (10.6)	1	1	1
Never walk	N	204(55.7)	38(10.4)	1	1	1
barefooted	Y	118(32.2)	6(1.6)	0.31 (0.13-0.71)	0.23 (0.06-0.80)	0.025
Wash feet	N	1 (0.27)	42 (11.5)	1	1	1
daily	Y	52 (14.2)	271 (74.2)	0.11 (0.01-0.85)	0.09 (0.01-0.75)	0.026
Age of	15-24	58(15.84)	19 (5.1)	1	1	1
patients	25-34	80 (22.13)	8 2.18)	0.40 (0.06-2.52)	47.7 (3.96-574)	0.06
	35-44	81 (22.13)	6 (1.63)	0.20 (0.03-1.26)	5.36 (0.63-45)	0.124
	45-54	61 (16.67)	6 (1.64)	0.15 (0.02-0.98)	1.93 (0.30-12)	0.482
	55-64	43 (11.75)	2 (0.5)	0.19 (0.03-1.30)	0.93 (0.14-6.19)	0.940
	65+	1 (0.27)	1 (0.27)	0.09 (0.01-0.84)	1.36(0.20-8.97)	0.744
Clinical	Stage 1	1 (0.27)	1 (0.27)	1	1	1
Stage	Stage 2	133 (36.3)	26 (7.01)	0.39 (0.06-2.24)	0.56 (0.01-22.3)	0.762
	Stage 3	102 (27.9)	13 (3.55)	0.26 (0.04-1.53)	0.68 (0.01-27.9)	0.839
	Stage 4	62 (16.9)	4 (1.36)	0.13 (0.01-0.93)	0.46 (0.01-21.9)	0.697
	Stage 5	24 (6.5)	0	-	-	-
Mossy	Y	194 (53)	32 (8.7)	2.06 (1-4.2)	1.19 (0.43-3.2)	0.739
appearance	N	124 (33.8)	13 (3.5)	1	1	1
Presence of	Y	199 (54.3)	30 (8.2)	1.53 (0.7-3.04)	0.55 (0.27-2.0)	0.737
wound	N	260 (71.0)	22 (6)	1	1	1

Y* = Yes N* = No COR = Crude Odds Ratio; AOR = Adjusted Odds Ratio

Social Stigma

Approximately one in three(125, 33.8%) people with podocniosis mentioned that they had experienced one or more forms of social stigma at school, church, within marriage, at the market place or at feasts. Stigma took the form of being excluded, shunned, pointed or gestured at, and not having products bought at market.

Factors Related to Footwear, Personal Hygiene and Walking Experience

The experience and attitudes of respondents towards footwear and personal hygiene were assessed. The majority (348, 94.1%) of people with podocniosis had no problem finding enough water and took an average of 22 minutes to reach a water source. The majority (315, 85.1%) of people with podocniosis washed their feet at least once per day (mean 1.4± 0.086), and 79

(21.4%) washed their feet with soap daily. Almost all (345, 94.3%) had washed their feet on the night before the interview was conducted. Foot washing behaviour did not change in 97 (26.2%) people with podoconiosis after their leg started to swell. The mean age to first start wearing shoes was 25.94 ± 13.83 (range 4-95) years. During the interview, 162 (43.8%) were wearing closed plastic shoes, while 32 (8.6%) were barefoot. A small but important subset (21, 5.7%) had never worn shoes.

Discussion

Burden assessment using a household census enables the number of people with podoconiosis within a district to be determined, and provides information on their distribution within the district. Such information is important for planning and implementing podoconiosis interventions in endemic districts. Our study identified that the prevalence of podoconiosis in Wayu Tuka *Woreda* in 2015 was 3.05%. The prevalence was higher among females than males and increased with age. The male to female ratio was 1:1.58 and the economically active age group (15-64 years of age) was heavily affected. ALA episodes were a major cause of morbidity, and patients' ability to work was impaired by ALA episodes. Patients also experienced significant stigma in a range of settings. The habits of never walking barefoot and daily foot hygiene were both independently associated with reduced odds of ALA.

At 3.05 %, (95% CI = 2.9% to 3.2%), the prevalence of podoconiosis in those aged 15 years and older in Wayu Tuka *Woreda* was slightly greater than that reported from Gulliso *Woreda* in West Wollega, 2.8%[6], but lower than that reported from Debre Elias *woreda* (3.3%) and Dembecha *woreda* (3.4%)[7], among residents of Midakegn, district, central Ethiopia (7.4%)[20], and Ocholo village (5.1%) [21] and Wolayta zone (5.5%) of southern Ethiopia [11]. However, it falls within the earliest national estimate of 0.4% to 3.7% across fifty-six markets[22]. Podoconiosis distribution shows significant geographic variation according to level of elevation and precipitation[15,23], and the prevalence estimated in Wayu Tuka *woreda* falls within the variation demonstrated in Oromia region in the recent nationwide mapping[15,23].

Male to female sex ratio was 1:1.58, which is consistent with several recent studies conducted in other areas, including the national study[24], Gulliso (1:1.26)[6] and Gojjam, northern Ethiopia (0.98:1)[7]. The risk in females may be enhanced as they shoulder the greatest burden of agricultural work and are less likely to own shoes than men. In Ethiopia, activities such as fetching water, cooking food, washing clothes, farming and buying goods from local markets are their daily duties and responsibilities. Podoconiosis is heavily affected the economically active

1 age group in this study. Studies in northern Ethiopia and Gulliso, West Wollega, have also
2 shown this age group to be strongly affected[6,7].

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4 Episodes of ALA had been experienced in the past year by 88.8% of patients, a slightly lower
5 proportion than found in Gulliso *Woreda* (97%). Some patients linked ALA with “*chagino*” (the
6 time around the new moon, often associated in local understanding with weather changes). ALA
7 was not significantly associated with sex or age at onset of illness, consistent with the study in
8 West Wollega[6]. Activities were impaired by lymphoedema and ALA in about three-quarters of
9 patients. During ALA, patients experienced severe pain and had to stay in bed for several days.
10 A study conducted in northern Ethiopia showed that three in five patients claimed their
11 ‘movement’ was impaired by podoconiosis and one in four by ALA[19]. In this study, ALA
12 had considerably more impact on ability to work than previous studies. An average total of 150
13 days (five months) was lost by patients in Wayu Tuka *woreda* annually, six times that recorded
14 in Gulliso *woreda* (24 working days lost on average)[6]. Earlier studies showed that people with
15 podoconiosis were about half as productive as unaffected individuals, and that medical costs and
16 productivity losses exceeded US\$16 million per year in one zone (with population of 1.8 million)
17 in southern Ethiopia. According to this study, most patients did not completely stop work, but
18 spent only 3.56 ± 2.87 hours per day on economic activity compared to the 6.52 ± 2.53 hours
19 worked by controls. Female patients spent 3.45 hours less on domestic activity compared to
20 matched controls [12].

21
22 One in four patients (25%) experienced stigma in this study. In contrast a study conducted in
23 northern Ethiopia showed that about 13% of patients had experienced one or more forms of
24 social stigma at school, church, or in the market place[18]. Stigma is increasingly being
25 recognized as an obstacle to good health and a barrier to accessing healthcare. Health-related
26 stigma affects the life chances of individuals, increasing their exposure to risks and limiting
27 access to protective factors, potentially adding to their burden of disease or disability[12,18]. The
28 main reasons for prevailing discrimination against patients and affected families are
29 the erroneous beliefs that podoconiosis cannot be prevented, treated or controlled; that it is
30 associated with curses; and that it runs in families through hereditary factors that make disease
31 inevitable[25,26].

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33 Most patients could reach a water source in an average 22 minute walking round trip. Another
34 study in western Ethiopia also claimed that patients could access water with a walk of ‘only’
35 20minutes[6], however WHO defines access to drinking water as “availability of at least
36 20L/person/day/within 30 minutes’ walk’[27]. Patients may not have to walk far for water, but
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1 whether they can access adequate water is another question. Patients who wash their feet at least
2 once per day are less likely to experience ALA. In Wayu Tuka, 85% of patients washed their feet
3 at least once per day, a larger proportion than in Gulliso(66.7%[16]). However, a lower
4 proportion of patients used soap daily to wash their feet than in Gulliso (21.4% vs. 58%,
5 respectively). Using shoes regularly and washing feet with soap consistently was uncommon
6 among study subjects in Wayu Tuka *Woreda*. Our study showed there were several challenges to
7 primary and secondary prevention of podoconiosis. Inconsistent shoe-wearing was identified
8 among patients who owned shoes. Although few respondents were barefoot, the shoes they were
9 wearing (open plastic or open tyre) were not protecting them from irritant soil. The other issue
10 was the average age at which they started wearing shoes: at 25 years, this indicated prolonged
11 contact with soil and delay in protection.
12

13 This study used a large scale community-based house to house survey in all *kebeles* of
14 Wayu Tuka *woreda*, followed by detailed study of podoconiosis patients. This provides a
15 complete profile of people with podoconiosis in the district. Nonetheless, the study is not without
16 limitations. A clinical algorithm was used to differentiate podoconiosis from other disease
17 causing leg swelling in such areas. Had a serological test been available, it would have helped
18 exclude lymphatic filariasis, the most common phenocopy in tropical areas. However, given that
19 the study area is at 2,200m above sea level, transmission of filaria is extremely unlikely.
20

21 We recommend strong prevention and morbidity management interventions to address this
22 developmental challenge. These interventions will require collaboration between local
23 government and non-government stakeholders, and integration with existing programmes
24 addressing water and sanitation, neglected tropical diseases and chronic diseases.
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Competing interests

The authors declare that they have no competing interests.

Authors' contributions

KB designed the study, carried out data collection and prepared the first draft of the manuscript. KD, GD, GT and AS revised study design. TA made field logistic arrangements. KB drafted the manuscript. KD, GD and AS revised the manuscript. All authors read and approved the final manuscript.

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Appendix 1: Questionnaire

Interviewer’s name (HEW) _____ HEW code _____ sign. _____

Date ____/____/____

Registration Format (Wayu Tuka Woreda) Kebele _____ ‘Zone’ _____

No	HH	HH mem	Do you know any patient With podoconiosis in your family?	How many?	First name	Fathers name	Sex 1.M 2.F	Age	Marital status
#	#	#	1 Yes2.No	#				#	#
1									
2									
3									
4									
5									
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Detailed study

Kebele _____ Zone _____ Nurse _____ Nurse code _____

Consent: we would like to ask you some questions to understand the problem of podoconiosis in your area. We also want to examine your legs .we hope that this will help plan services for people with this condition. Thank you for participating in this study.

1. REGISTRATION

1.1. Name _____ 1.2. Sex: 1.Male 2. Female 1.3.Age _____ years

1.4 .Number of years lived in this kebele _____ years

2. HISTORY OF DISEASE AND PERCEPTION ABOUT PODOCONOISIS

2.1 How old were you (age) when you first noticed your legs are swollen? _____ Years

2.2 How long after the swelling you try to get treatment care? _____ Years

2.3 Where did you go first?

1. Health center
2. Health post
3. Hospital
4. Podoconiosis treatment center
5. Pharmacy/drug store
6. Traditional/healers
7. Others _____

2.4 When were you last sick with a painful swollen leg?

1. ____ wks ago
2. ____ months ago
3. ____ years ago
4. Never (Go to Q 2.6)

INTERVIEWER: MAY I LOOK AT YOUR LEG?

2.5.1 Has the person got acute attack during the interview?

1. Yes
2. No (GO TO Q2.6.1)

2.5.2. If yes to Q2.5.1: what signs and symptoms do you observe?

1. Oozing
2. Tenderness (Pain in touch)
3. 3. Hot (on touch)
4. 4. Fever
5. 5. Swollen lymph node

2.6.1 Did you look for help?

1. Yes
2. No (GO TO Q2.6.3)

2.6.2. If 'YES' to Q2.6.1: where did you seek help?

1. Health center
2. Health post
3. Hospital
4. Podoconiosis treatment center
5. Pharmacy/ drug store
6. Traditional healers

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2.6.3 Did you stay in bed?

1. Yes

1. No (Go to Q2.6.5)

2.6.4 If “Yes” to Q2.6.3: How long you stay in bed? _____ days

2.6.5. How often in the last 12 months did you have this problem? ___times /every___ months

2.6.6. Which time of the year is this problem worse?

1. All the time

2. Rainy season

3. Hot and dry season

4. During chagino

5. Others _____

2.6.7. What precipitate acute attack symptoms?

1. Hard (labours) work

2. A little more than usual work

3. Long walk

4. Other _____

2.6.8. How do you usually cope with (react towards) acute attack episodes?

1. Resort to less exertive work

2. Stay in bed

3. Other (specify) _____

PERCEPTION ON CAUSE, PREVENTION AND CONTROL OF PODOCONIOSIS

2.7. Why do you think you have podoconiosis? (NEVER READ ANSWERS.PROBE. CIRCLE ALL THAT APPLY)

1. I am barefooted

2. I or my families are cursed

3. This is a familial problem (it runs through ‘blood/ bone’ of our family)

4. I got it following contagion with an affected person (e.g. wore his/her shoes)

5. Following snake bite

6. Following exposure to condensation

7. I don’t know

2.9. Do you think podoconiosis can be prevented?

1. Yes

2. No - CIRCLE AND GO TO Q2.11

3. I don't know(GO TO Q 2.11)

2.10 If the answer to Q2.9 was 'Yes': How can podoconiosis be prevented? (PLEASE DON'T READ THE ANSWERS. PROBE AND CIRCLE ALL THAT APPLY)

1. Wearing shoes protective of exposure to soil regularly
2. Washing feet with soap and water regularly
3. Avoiding marriage with affected families
4. Avoiding contact with affected

2.11. Do you think progression of podoconiosis can be controlled at early stages of the condition/is it curable?

1. Yes
2. No ...CIRCLE AND GO TO Q2.13
3. I don't know GO TO Q2.13

2.12. If the answer to Q 2.11 was 'Yes' how can podoconiosis be controlled at early stage? (PLEASE DON'T READ THE ANSWERS PROBE AND CIRCLE ALL THAT APPLY)

1. Wearing shoes protective of exposure to soil regularly
2. Washing feet with soap and water regularly
3. Avoiding marriage with affected families
4. Avoiding contact with affected

2.13. If the answer to Q2.12 was No: why do you think podoconiosis cannot be controlled (cured)? (PLEASE DON'T READ THE ANSWERS PROBE AND CIRCLE ALL THAT APPLY)

1. It is familial (runs through 'blood/bone')
2. There is no drug for it
3. I have never seen a cured person
4. Others specify_____

SOCIAL STIGMA

2.8. Did you experience any social stigma / discrimination because you have podoconiosis? (READ B-F ONE BY ONE. IF THEY ANSWER YES, UNDERLINE THE POINTS MENTIONED IN THE BRACKET. PROBE FOR OTHER EXPERIENCES PUT THAT UNDER 7)

1. No .people treat me like any person else.
2. Yes, schooling (drop out, shunning pointing fingers, pinching nose)
3. Yes, church (exclusion, shunning, pointing fingers, pinching nose)

4. Yes, marriage (exclusion, shunning, pointing fingers, pinching nose)
5. Yes, market place (people are not interested to buy my products)
6. Yes, feasts (exclusion, shunning, pointing fingers, pinching nose)
7. Others (specify) _____

2.14 Examination

	2.14.1 stage 1-5	2.14.2 mossy 1. Yes 2. No	2.14.3 wound 1. Yes 2. No	2.14.4 type(watery, bag, nodular, mixed)	2.14.5 Greatest below knee leg circumference (cm)
1. right leg					
2. left leg					

3. BACKGROUND

3.11. Educational status:

1. cannot read and write
2. Read and write

3.12. If the answer to Q 3.11 is (2) what grade are you? _____

3.2 Main occupation

1. Farming
2. Weaving
3. Daily labourer
4. House
5. Others _____

3.3. Marital status

1. Single.
2. Married
3. Widowed
4. Divorced
5. Separated

3.4. FAMILY HISTORY

(NOTE: THIS PART IS A VERY SENSITIVE, YET RELEVANT SECTION. SO YOU SHOULD BE EXTRA POLITE AND EXPLAIN THAT ALL INFORMATION WILL BE KEPT CONFIDENTIAL. IN ADDITION MENTION THAT THIS INFORMATION WILL BE

RELEVANT FOR TARGETING DISEASE PREVENTION AND TREATMENT PROGRAMS)

3.4.1. Does any member of your family (meaning relatives such as parents, grandparents, cousins, siblings, or children) have podoconiosis?

1. Yes
2. No _____ GO TO Q3.4.3

3.4.2 If “Yes” to Q3.4.1: how are you related? (PROBE FOR OTHER CATEGORIES)

	a. #	b. sex 1.M 2.F	Still alive? 1. Y2. N
3.4.2.1 Grandparent?			
3.4.2.2parent?			
3.4.2.3sibling?			
3.4.2.4child?			
3.4.2.5other?			

3.4.3 How many member of your household (together with you) are affected? _____

3.4.4 Is that person available for interview? 1. Yes 2. No

NOTE TO INTERVIEWER: IF THE ANSWER IS “YES”, RECORD THE FOLLOWING AND GIVE APPOINTMENT FOR NEXT DAY INTERVIEW BY A NURSE.

Name _____ Age ____ Sex 1. Male 2. Female

3.4.5.1 Are any children in the house complaining of problems with feet? 1. Yes 2. No

3.4.5.2 If Yes to Q3.4.5.1: what are the signs and symptoms?

NOTE TO INTERVIEWER: IF THE ANSWER IS “YES”, RECORD THE FOLLOWING AND GIVE APPOINTMENT FOR NEXT DAY INTERVIEW BY A NURSE.

Name _____ Age ____ Sex 1. Male 2. Female

3.4.6 Why do you think there are multiple affected family members in your

Family (household)? (CIRCLE ALL ANSWERS SPECIFIED)

1. Because the disease is contagious
2. Because the disease runs through families (blood/ bone)
3. Because the family is cursed/ any spiritual connection
4. Because the family is poor and cannot afford shoes
5. I don't know
6. Others specify
- 7.

4. WEARING SHOES

4.1.1. How old were you when you first got shoes? ____ Years

4.1.2 How old were you when you first got shoes? ____ Years

4.2 interviewers: observe and describe the shoes the person is now wearing.

1. Hard plastic open
2. Hard plastic covered
3. 'Barabaso'
4. Leather
5. 'Shara'/canvass
6. Bare footed

4.3. When you usually not wear shoes?

1. During farming
2. During Non –Farming Work
3. At Home
4. I Am Usually Bare Footed
5. I Am Always Barefooted

4.4. How many pairs of shoes do you have? _____

4.5. How many pairs of shoes do you need / year? _____

5. WASHING FEET

5.1 can you get enough water?

1. Yes (go to q 5.3)
2. No

5.2 If no q5.1: what was the problem?

1. Seasonal shortage
2. Distance
3. Others specify _____

5.3. How long (in minutes) do you go to the nearest water source (1 way)? _____ Minutes

5.4. Did you wash your feet last night?

1. Yes
2. No

5.5 If yes to q5.4. Interviewer: please observe and describe the cleanliness of the feet

1. Clean and intact
2. Dirty

3. Cracked

4. Dirty and cracked

5.6 How many times do you wash your feet? _____ Times

5.7. After your feet started swelling, did your foot washing behaviours changed?

1. Yes

2. No (go to q 5.9)

5.8. If yes to q5.7: do you wash your feet more often / less often?

1. More often

2. Less often

5.9. Do you use soap for your feet?

1. Yes

2. No

5.10. If “yes” to q5.6: how many times/ times do you wash your feet with soap? _____times

DISTANCE WALKED

6.1. How long does it take to go to your nearest field? _____min/hrs

6.2. How many times do you go to your field each month? _____times

6.3. How long does it take to go to your nearest market month? _____minutes

6.4. How often do you go to market each month? _____times

6.5. ASK ANOTHER PERSON OF THE HOUSEHOLD: How many times last year was the person sick with acute attack? _____

7. DISABLING EFFECTS (FUNCTIONAL IMPAIRMENT)

7.1. Over the past 30 days, has podocoinosis or acute attack of ALA hampered movement (walking, travelling to markets etc) (MORE ONE ANSWER POSSIBLE)

1. Yes, effect of the disease

2. Yes effect of acute attacks

3. Uncertain

4. No

7.2. ASK WOMEN: over the past 30 days, has podocoinosis or acute attack of ALA hampered any house hold chores (cleaning, cooking, child care etc) (MORE THAN ONE ANSWERS POSSIBLE)

1. Yes, effect of the disease

2. Yes effect of acute attacks

3. Uncertain

4. Not applicable (circle this if the respondent is a man)

7.3. ASK MEN: Over the past 30 days, has podoconiosis or acute attack of ALA hampered daily/ occupational work? (MORE THAN ONE ANSWER IS POSSIBLE)

1. Yes, effect of the disease
2. Yes effect of acute attacks
3. Uncertain 4. not applicable (if a woman)

7.4. If either 7.2 or 7.3 is 'yes': what was the effect of the disease? (Read each answer & circle all that apply)

1. Work less hours
2. Worked less energy
3. Absence from work
4. Earned less income
5. Reduced productivity (e.g. harvest from agriculture)
6. Others (specify) _____

7.5. How has podoconiosis affected your work life over a long period of time (many months or years)? (Read each answer and circle all that apply)

1. I work only occasional
2. I work less hours
3. I restored to less remunerative work
4. I avoided physically demanding tasks
5. I totally stopped work
6. Other _____

7.6. How do you rate your financial status compared to your fellow neighbours with the same occupation and family size?

1. About the same
2. I am poorer
3. I am better off

7.7. If the answer to q 7.6 was '2': did your financial status worsen after your family became affected by podoconiosis?

1. Yes
2. No

We have finished the interview. Thank you for time and participation!

Appendix 2: Standard Training Material Used To Train Nurses and HEWs

Podoconiosis: Differential Diagnosis, & Clinical Staging (Professor G. Davey)

Differential diagnosis - which other conditions could it be?

- | | |
|-------------------------|--------------------------|
| 1• Filarial Lymphoedema | 3• Leprosy |
| 2• Onchocerciasis | 4• deep fungal infection |

1. Filarial lymphoedema

Ask: Is patient from lowland area? Did the swelling start at the foot or higher up?

Look: Is leg swelling very asymmetrical (one leg 'normal')?

Examine: Check the groin for swollen lymph node

Do: Refer for tablet treatment at Health Centre, invite back for usual MFTPA leg care.

2. Onchocerciasis

Ask: Does patient have itchy trunk or nodules?

Look: Look for onchodermatitis, pretibial depigmentation, onchocercomas, eye changes

Examine: Examine skin of whole body, check the groin for lymph nodes

Do: Refer for treatment of onchocerciasis, invite back for usual MFTPA leg care.

3. Leprosy

- Exaggerated eyebrow area
- Shiny skin on feet
- Toes may look short
- Foot ulcer may be present
- Patient cannot feel

Ask: Has the patient noticed any skin changes?

Look: Are there rough raised skin lesions?

Examine: For thickened nerves at the elbow or behind the ear; for foot ulcers; check if patient can feel you touch his feet?

Do: Refer for leprosy treatment. Invite back for follow up MFTPA foot care.

5. Fungal

Deep fungal infection Lump on one foot May have small black dots on surface

Do: Refer to surgeon for biopsy, anti-fungal treatment/amputation

CLINICAL STAGING

Why is staging important?

- So program planners can assess burden of disease in given area;
- So patients can see effect of self-treatment;
- So health professionals can document effectiveness of medical and surgical treatment;
- So researchers can document effects of public health interventions.

Stage 0. No disease present.

Stage 1. Swelling reversible overnight.

Stage 2. Persistent below-knee swelling; if present, knobs or bumps are below the ankle
ONLY

Stage 3. Persistent below-knee swelling; knobs or bumps present above the ankle.

Stage 4. Persistent above-knee swelling; knobs or bumps present at any location.

Stage 5. Joint fixation; swelling at any place in the foot or leg. (X-rays may show tuft erosion and loss of bone density)

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract Done(Page1-2) (b) Provide in the abstract an informative and balanced summary of what was done and what was found Done
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported Done(Page 4)
Objectives	3	State specific objectives, including any prespecified hypotheses Done(Page 5)
Methods		
Study design	4	Present key elements of study design early in the paper Done(Page 5)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection Done (page 5)
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants Done (Page 5)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable Done (Page 6)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group Done (page 5-6)
Bias	9	Describe any efforts to address potential sources of bias Done (Page 14)
Study size	10	Explain how the study size was arrived at Done (Page 6)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why Done (Page 6)
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding Done (page 6) (b) Describe any methods used to examine subgroups and interactions Done (Page 6) (c) Explain how missing data were addressed Not applicable (d) If applicable, describe analytical methods taking account of sampling strategy Done (Page 6) (e) Describe any sensitivity analyses Not applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed Done (Page 7) (b) Give reasons for non-participation at each stage Done (page 7) (c) Consider use of a flow diagram Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders Done (Page 7) (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures Done (Page 7)
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included Done (page 7-10)

		(b) Report category boundaries when continuous variables were categorized Done
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses Not applicable
Discussion		
Key results	18	Summarise key results with reference to study objectives Done(Page 12)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias Done (Page 14)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence Done (Page 12-14)
Generalisability	21	Discuss the generalisability (external validity) of the study results Done
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based Done (page 15)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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BURDEN ASSESSMENT OF PODOCONIOSIS IN WAYU TUKA WOREDA, EAST WOLLEGA ZONE, WESTERN ETHIOPIA: A COMMUNITY BASED CROSS-SECTIONAL STUDY

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6 **BURDEN ASSESSMENT OF PODOCONIOSIS IN WAYU TUKA WOREDA, EAST**
7 **WOLLEGA ZONE, WESTERN ETHIOPIA: A COMMUNITY BASED CROSS-**
8 **SECTIONAL STUDY**
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Abstract

Objective: Podoconiosis is a neglected tropical disease characterized by slowly progressive swelling of the foot and lower leg. It is prevalent among subsistence barefoot farmers who live and work in highland areas of the tropics. This study was conducted in Wayu Tuka *woreda* (district), western Ethiopia to determine the prevalence of podoconiosis and assess factors associated with acute lymphangioadenitis (ALA) episodes.

Methods and analysis: A two phase, community-based cross-sectional study was conducted between January and March 2015. First, all households in the district were surveyed to determine the prevalence of podoconiosis. This was followed by a second phase in which 366 people with podoconiosis from four randomly selected *kebeles* (sub districts) were assessed for clinical features of the disease, shoe-wearing habits, personal hygiene, social stigma and functional impairment. Data entered into Epi DATA were then exported to SPSS. Logistic regression analysis was conducted to identify factors associated with ALA.

Results: Prevalence of podoconiosis in the population was 3.05 % (1197/39256) (95% CI = 2.9% to 3.2%). The prevalence was significantly higher among women than men (3.67% vs. 2.4%). Most (92.2%) people with podoconiosis were in the economically active age group (15-64 years) in the first phase survey. Of participants in the second phase of the study, 43% had stage 2 disease and 38.1% had 'moss'-like skin changes. People with podoconiosis had on average 23.3 episodes of ALA/year and on average, each person with podoconiosis lost 149.5 days of activity/year. Never walking barefoot and daily foot washing were both associated with decreased odds of ALA (AOR=0.23; 95% CI: 0.06-0.80 and 0.09; 95% CI; 0.01-0.75, respectively).

Conclusion: A relatively high prevalence of podoconiosis, frequent ALA episodes and considerable decreases in daily activities were identified in this district. Footwear use and daily foot hygiene were associated with decreased odds of ALA. We recommend prevention and morbidity management interventions to address this developmental challenge.

Key words: Acute adenolymphangitis, Burden, Ethiopia, Podoconiosis

Strengths and Limitations of this study

- The study used a complete census of all podoconiosis cases in one district. The study provides a profile of people with podoconiosis in the district, which is important for rational deployment of limited resources towards prevention and treatment of the disease.
- A limitation of the study is case identification – this was not supported by serological tests to exclude lymphatic filariasis.
- A second limitation was that self-report of ALA was not validated in any way.

Background

Podoconiosis is a disabling and stigmatizing neglected tropical disease (NTD), which affects the lower limb. It is caused by longstanding exposure to red clay soil of volcanic origin[1]. It is characterized by the development of persistent swelling of the foot which progresses to the dorsum and gradually extends up the lower leg. Podoconiosis affects the lower limbs, and the swelling is usually limited to below the knees[2,3].

Podoconiosis can be distinguished from filarial elephantiasis through history and clinical examination: podoconiosis develops first in the foot, it causes bilateral but asymmetric swelling often confined to the lower leg, and groin involvement is rare in podoconiosis. In contrast, the swelling of lymphatic filariasis is commonly found above the knee and often involves the groin. Another common differential diagnosis is leprosy lymphoedema, but podoconiosis can be distinguished from this because sensation persists in the toes and forefoot, and trophic ulcers, thickened nerves and hand involvement are not found[4].

Acute adenolymphangitis (ALA) is a common and disabling complication of podoconiosis lymphoedema, yet has been very little investigated to date. According to studies conducted in northern and western Ethiopia, podoconiosis patients experienced on average five episodes of ALA per year and up to 90 days per year incapacitated by ALA [5,6]. In filarial lymphoedema (LF), episodes of ALA have been shown to accelerate damage to peripheral lymphatic vessels and to lead to fibrosis[7].

Prevalence of podoconiosis is high in many highland parts of Africa: Cameroon[8], Ethiopia[9]. In Ethiopia, prevalence of podoconiosis is about 5% in areas with irritant soil[1], eleven million Ethiopians (18% of the population) are at risk through exposure to the irritant soil [1] and up to 90% of affected individuals are from the most economically active age groups[5]. In a study in southern Ethiopia, it was found that affected individuals lose 45% of their total productive work days. Direct and productivity cost of podoconiosis in a group of 1.5million inhabitants have been estimated at US\$16million a year, imposing an economic burden of \$208million per year in Ethiopia [10].

Recently, podoconiosis and other Neglected Tropical Diseases (NTDs) have been receiving attention in Ethiopia[11]. The Federal Ministry of Health of Ethiopia endorsed inclusion of podoconiosis in the National Master Plan for Neglected Tropical Diseases in 2011, and nationwide mapping of podoconiosis and lymphatic filariasis was conducted in 2013[11-13]. While *woreda*-level burden of disease as manifested by leg swelling has been described in several recent studies [5,6,14], very little attention has been given to acute adenolymphadenitis

(ALA), another important sequela of podoconiosis. This study aimed to determine the burden of both podoconiosis lymphoedema and ALA in western Ethiopia.

Methods

Study Area and Period

The study was conducted in Wayu Tuka *woreda* (an equivalent of a district in Ethiopia), in East Wollega Zone, Oromia Region, western Ethiopia. It is located 324 Km from the capital Addis Ababa, has an altitude of 1700-2,200 metres above sea level and an average annual rainfall of 2,400 mm. The population of Wayu Tuka *woreda* is estimated at 75,970, living in 15,930 households [15], of which 95% are in rural areas and depend on subsistence farming for their living. This study was conducted from January-March, 2015. The study is reported according to STROBE Statement—Checklist for cross-sectional studies (Supplementary File 1).

Study Design and Sampling

A two phase cross-sectional community based study was conducted. In the first phase, all the households in the *woreda* were surveyed to determine the prevalence of podoconiosis and to identify peoples with podoconiosis for the second phase study. In the second phase, 366 people with podoconiosis from four randomly selected *kebeles* (an aggregate of villages and the smallest administrative unit in Ethiopia) were approached to assess clinical features of the disease, habits of shoe-wearing, personal hygiene, social stigma due to the disease and functional impairment.

Inclusion and Exclusion Criteria

All individuals who were willing to participate were included, however, in the second phase; people with podoconiosis with mental health problems precluding them answering questions with substantial recall were excluded.

Data Collection

Thirty Level 4-holder nurses employed as Health Extension Workers and two Bachelor of Science (BSc) nurse supervisors were recruited in the first phase survey, while ten Health Extension Workers and two BSc nurse supervisors were recruited for the second phase survey. The Health Extension Workers were responsible for house-to-house enumeration of podoconiosis cases and the interviewing and physical examination of people with podoconiosis). The nurses were responsible for supervising the activities of the Health Extension Workers. In households where there was more than one person with podoconiosis, all of them were invited to interview and physical examination including measurement of leg circumference. All field staff were trained for one day before carrying out data collection. The questionnaire included sections from earlier studies on podoconiosis (Supplementary File 2) [5,6,14] including history of condition, understanding about causes, stigma, family history and preventive

1 behaviours. The questionnaire was prepared in English, translated into Afaan Oromo (the local
2 language) and translated back to English to maintain consistency of the variables under
3 question. Health extension workers were trained to take informed consent from participants, to elicit
4 features that differentiate lymphoedema and leg swelling resulting from podoconiosis from other diseases
5 such as leprosy and lymphatic filariasis, to conduct clinical staging according to a standard method, to
6 assess for presence of ALA, and to measure leg circumference. A pre-test done in Jalallee kebele, in a
7 neighboring district, ensured reliability of enumeration and diagnostic skills.
8

9 Operational Definitions

10 **Acute Adenolymphangitis (ALA):** A reddish, hot, swollen leg with a painful groin [5,16].

11 **Chagino:** the time around the new moon, often associated in local understanding with weather
12 changes[5].

13 **Economically active age:** Any one between the ages of 15-65[10].

14 **Leg circumference:** The largest circumference between the level of the ankle and the knee
15 measured using a tape, to a precision level of the nearest centimetre[17].

16 **Mossy lesions:** Papillomatous horny lesions giving the skin a rough appearance.

17 **A person with podoconiosis:** An individual in an endemic area diagnosed by a trained nurse and
18 a health extension worker who fulfils all of the following diagnostic criteria: history of burning
19 sensation in the feet when the swelling started; visible swelling that started at the feet and
20 progressed upwards; with at least stage one of the five clinical stages of podoconiosis; and with
21 no known clinical signs or symptoms of leprosy or lymphatic filariasis[9].

22 Data Processing and Analysis

23 Data were entered into Epi DATA then exported to SPSS data version 20 and summarized in
24 tables. To identify risk factors associated with ALA, a bivariate logistic regression was
25 performed, and then multivariable logistic regression was conducted. A significance level of 0.05
26 was used as a cut-off.

27 Ethical Considerations

28 Ethical clearance was obtained from Wollega University Ethical Review Committee. After
29 discussing the study with the local authorities we obtained written approval to conduct the study
30 in all *kebeles*. The ultimate purpose of the study was explained and data were collected only
31 from those who gave written consent. The participants were informed of their rights including
32 ability to stop participating at any time or to skip questions they do not wish to respond to. For
33 individuals less than 18 years of age, consent was obtained from parents or guardians. People
34 with podoconiosis were advised to attend health clinics for management of the condition.
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RESULTS

Socio-Demographic Characteristics of People with Podoconiosis in Phase 1 Survey

The male to female ratio was 1:1.58. The mean (\pm SD) age of people with podoconiosis was 43.1 \pm 13.3 years. Slightly more than nine in ten (1,117, 93.3%) belonged to the economically active age group. The majority (95%) lived in rural areas and was reliant on subsistence farming. (Table 1).

Table 1 Socio demographic characteristics of people with podoconiosis in the phase 1 survey, Wayu Tuka *Woreda*, January to March 2015 (N = 1,197).

Characteristics	Category	N (%)
Marital Status	Single	131 (10.9%)
	Married	905 (75.6)
	Divorced	25 (2.1)
	Widowed	136 (11.4)
Family Size	1-4	653 (53.9)
	\geq 5	559 (46.1)

Burden of Podoconiosis

Prevalence of podoconiosis in the population was 3.05% (1,197/39,256, 95% CI = 2.9% to 3.2%). The prevalence was significantly higher among women than men (3.67% vs.2.40%). Prevalence disaggregated by age and sex is shown in Table 2.

Table 2. Prevalence of podoconiosis disaggregated by age and sex in Wayu Tuka *Woreda*

Age	Male			Female		
	Number examined	People with podoconiosis	Prevalence (%)	Number examined	People with podoconiosis	Prevalence (%)
15-24	8025	10	0.1	8801	9	0.1
25-34	4574	33	0.7	4516	83	1.8
35-44	3059	110	3.6	2888	199	6.9
45-54	1668	137	8.2	1765	199	11.3
55-64	1020	80	7.8	1064	148	13.9
65 ⁺	942	94	10.0	935	95	10.2
Total	19288	464	2.4	19968	733	3.7

Socio-Demographic Characteristics of People with Podoconiosis in the Phase 2 Study

A total of 366 people with podoconiosis were approached for the detailed study in four randomly selected *kebeles*. These participants consisted of 134 (36.6%) males and 232 (63.4%) females. On average, the respondents had lived in the study area for 38.64 \pm 18.24 years. Slightly more than nine in ten, 337 (92%), of the respondents belonged to the economically active age group.

More than 75% had no formal education, and the majority (346, 94.5%) of the study participants were farmers (Table 3).

Table 3: Socio Demographic characteristics of people with podoconiosis in the phase 2 study, Wayu Tuka *Woreda*, January to March, 2015 (n = 366).

Characteristics	Category	N (%)
Sex	Male	134 (36.6)
	Female	232 (63.4)
Age	15-24	25 (6.8)
	25-34	54 (14.8)
	35-44	88 (24)
	45-54	87 (23.7)
	55-64	67 (18.3)
	65 ⁺	45 (12.3)
Educational Status	Cannot read or write	279 (76.2)
	Can read and write	87 (23.8)
Occupation	Farming	346 (94.5)
	Others ¹	20 (5.5)
Marital Status	Single	81 (22.1)
	Married	208 (56.8)
	Others ²	77 (21.0)

Others¹ = begging, students, retired, Others²=widowed, divorced, separated

Clinical Characterization of Podoconiosis in Phase 2 Study.

People with podoconiosis in the four randomly selected *kebeles* were categorized into five clinical stages according to pre-existing clinical staging criteria[17]. The majority (159, 43.4%) had clinical stage two disease. The greatest below-knee leg circumference was 26.6±5.3cm (range 18-45). Table 4 summarizes clinical characteristics of podoconiosis.

Table 4. Clinical characterization of people with podoconiosis in phase 2 study, Wayu Tuka *Woreda*, January to March, 2015.

Characteristics	Category	N (%)
Clinical Stage (n=366)	One	2 (0.5)
	Two	159 (43.4)

	Three	115 (31.4)
	Four	66 (18.0)
	Five	24 (6.6)
Mossy Appearance (n=366)	Yes	141 (38.5)
	No	225 (61.5)
Wound (n=366)	Yes	138 (37.7)
	No	228 (62.3)
Leg Circumference (Cm, n=359)	18-27	220 (61.3)
	28-36	123 (34.3)
	37-45	16 (4.5)

Features of ALA

ALA is the major cause of morbidity in people with podoconiosis. The majority, (325, 88.8%), of people with podoconiosis had experienced ALA in the year before the survey. The most recent episode of ALA had occurred an average of 2.97 weeks before the study. On average, people with podoconiosis experienced 23.3 ± 14.4 ALA episodes/year, and on average, were bed bound for 6.42 ± 5.39 days; meaning that on average, each person with podoconiosis lost 149.5 days of activity per year. Nearly half (182, 49.8%) of the people with podoconiosis had ALA at the time the interview was conducted. More than one-third (38.4%) of people with podoconiosis reported that ALA episodes were worse during the rainy season. The major trigger of an ALA episode was prolonged walking (reported by 163, 44.1%). Many (137, 42.2%) had retired to bed without treatment at least once in the past year as a coping mechanism. During episodes of ALA, 40% of people with podoconiosis had sought treatment at a podoconiosis treatment clinic while 9.5% had not sought treatment of any kind (Table 5).

Table 5. Features of ALA among people with podoconiosis in Wayu Tuka *Woreda*, January -March 2015

Characteristics	Category	N (%)
ALA in year before survey (n=366)	Yes	325 (88.8)
	No	41 (11.2)
ALA at time of Interview (n=366)	Yes	182 (49.8)
	No	184 (50.2)
Time when ALA worsen (n=325)	Rainy season	142 (38.4)
	All the time	74 (32.1)

	During “Chagino”	68 (18.4)
	Hot and dry season	41 (11.1)
Triggers of acute attack (n=325)	Long walk	163 (44.1)
	Hard physical work	66 (17.8)
	Walking barefoot	64 (17.3)
	More work than usual	32 (8.6)
ALA coping mechanisms (n=325)	Stay in bed	137 (42.2)
	Resort to less physical work	120 (36.9)
	Get treatment	68 (20.9)
Place treated (n=366)	Podoconiosis treatment centre	148 (40.4)
	Health Facilities*	93 (25.4)
	Traditional	90 (24.5)
	Treatment not sought	35 (9.5)

*NB. Health Facilities = Health Center, Health Post, Hospital and Pharmacy/drug store

Factors Associated with ALA

In multivariate analysis, never walking barefoot and daily foot washing was associated with lower odds of ALA. People with podoconiosis who never walked barefoot had one quarter the odds of ALA than those who walked barefoot at times [AOR=0.23, 95% CI 0.06-0.80, p=0.025]. People with podoconiosis who washed their feet daily had one twelfth the odds of ALA of those who did not [AOR=0.09, 95% CI 0.01-0.75, p = 0.023]. Variables such as patient’s age, clinical stage of disease, mossy appearance, and presence of wound were associated in the bivariate analysis but these associations did not persist after multiple logistic regressions (Table 6).

Table 6: Factors associated with ALA in people with podoconiosis Wayu Tuka *Woreda*, January - March 2015

Variable	ALA		COR (95%CI)	AOR (95%CI)	P-value	
	Yes (%)	No (%)				
Situations in which people with podoconiosis walk barefoot						
Farming	Y*	83 (22.7)	242 (66)	1.14 (0.54-2.29)	1.46 (0.6-3.6)	0.403
	N [†]	17 (4.6)	24 (6.5)	1	1	
Non-Farming	Y	74 (20)	251 (68.5)	0.56 (0.24-1.3)	0.39 (0.14-1.05)	0.063
	N	34 (9.2)	20 (5.4)	1	1	
Home	Y	78 (21.3)	247 (67.5)	1.84 (0.86-3.94)	1.48 (0.49-4.1)	0.384

	N	20 (5.5)	21 (5.7)	1	1	1
Always	Y	26 (7.01)	299 (81.7)	0.49 (0.09-2.49)	0.41 (0.06-2.54)	0.335
barefooted	N	2 (0.54)	39 (10.6)	1	1	1
Never walk	N	204(55.7)	38(10.4)	1	1	1
barefooted	Y	118(32.2)	6(1.6)	0.31 (0.13-0.71)	0.23 (0.06-0.80)	0.025
Wash feet	N	1 (0.27)	42 (11.5)	1	1	1
daily	Y	52 (14.2)	271 (74.2)	0.11 (0.01-0.85)	0.09 (0.01-0.75)	0.026
Age of	15-24	58(15.84)	19 (5.1)	1	1	1
patients	25-34	80 (22.13)	8 2.18)	0.40 (0.06-2.52)	47.7 (3.96-574)	0.06
	35-44	81 (22.13)	6 (1.63)	0.20 (0.03-1.26)	5.36 (0.63-45)	0.124
	45-54	61 (16.67)	6 (1.64)	0.15 (0.02-0.98)	1.93 (0.30-12)	0.482
	55-64	43 (11.75)	2 (0.5)	0.19 (0.03-1.30)	0.93 (0.14-6.19)	0.940
	65+	1 (0.27)	1 (0.27)	0.09 (0.01-0.84)	1.36(0.20-8.97)	0.744
Clinical	Stage 1	1 (0.27)	1 (0.27)	1	1	1
Stage	Stage 2	133 (36.3)	26 (7.01)	0.39 (0.06-2.24)	0.56 (0.01-22.3)	0.762
	Stage 3	102 (27.9)	13 (3.55)	0.26 (0.04-1.53)	0.68 (0.01-27.9)	0.839
	Stage 4	62 (16.9)	4 (1.36)	0.13 (0.01-0.93)	0.46 (0.01-21.9)	0.697
	Stage 5	24 (6.5)	0	-	-	-
Mossy	Y	194 (53)	32 (8.7)	2.06 (1-4.2)	1.19 (0.43-3.2)	0.739
appearance	N	124 (33.8)	13 (3.5)	1	1	1
Presence of	Y	199 (54.3)	30 (8.2)	1.53 (0.7-3.04)	0.55 (0.27-2.0)	0.737
wound	N	260 (71.0)	22 (6)	1	1	1

Y* = Yes N* = No COR = Crude Odds Ratio; AOR = Adjusted Odds Ratio

Social Stigma

Approximately one in three (125, 33.8%) people with podoconiosis mentioned that they had experienced one or more forms of social stigma at school, church, within marriage, at the market place or at feasts. Stigma took the form of being excluded, shunned, pointed or gestured at, and not having products bought at market.

Factors Related to Footwear, Personal Hygiene and Walking Experience

The experience and attitudes of respondents towards footwear and personal hygiene were assessed. The majority (348, 94.1%) of people with podoconiosis had no problem finding enough water and took an average of 22 minutes to reach a water source. The majority (315, 85.1%) of people with podoconiosis washed their feet at least once per day (mean 1.4± 0.086), and 79

(21.4%) washed their feet with soap daily. Almost all (345, 94.3%) had washed their feet on the night before the interview was conducted. Foot washing behaviour did not change in 97 (26.2%) people with podoconiosis after their leg started to swell. The mean age to first start wearing shoes was 25.94 ± 13.83 (range 4-95) years. During the interview, 162 (43.8%) were wearing closed plastic shoes, while 32 (8.6%) were barefoot. A small but important subset (21, 5.7%) had never worn shoes.

Discussion

Burden assessment using a household census enables the number of people with podoconiosis within a district to be determined, and provides information on their distribution within the district. Such information is important for planning and implementing podoconiosis interventions in endemic districts. Our study identified that the prevalence of podoconiosis in Wayu Tuka *Woreda* in 2015 was 3.05%. The prevalence was higher among females than males and increased with age. The male to female ratio was 1:1.58 and the economically active age group (15-64 years of age) was heavily affected. ALA episodes were a major cause of morbidity, and patients' ability to work was impaired by ALA episodes. Patients also experienced significant stigma in a range of settings. The habits of never walking barefoot and daily foot hygiene were both independently associated with reduced odds of ALA.

At 3.05 % (95% CI = 2.9% to 3.2%), the prevalence of podoconiosis in those aged 15 years and older in Wayu Tuka *Woreda* was slightly greater than that reported from Gulliso *Woreda* in West Wollega, 2.8%[5], but lower than that reported from Debre Elias *woreda* (3.3%) and Dembecha *woreda* (3.4%)[6], among residents of Midakegn, district, central Ethiopia (7.4%)[18], and Ocholo village (5.1%) [19] and Wolayta zone (5.5%) of southern Ethiopia[9]. However, it falls within the earliest national estimate of 0.4% to 3.7% across fifty-six markets[20]. Podoconiosis distribution shows significant geographic variation according to level of elevation and precipitation[13,21], and the prevalence estimated in Wayu Tuka *woreda* falls within the variation demonstrated in Oromia region in the recent nationwide mapping[13,21].

Male to female sex ratio was 1:1.58, which is consistent with several recent studies conducted in other areas, including the national study[22], Gulliso (1:1.26)[5] and Gojjam, northern Ethiopia (0.98:1)[6]. The risk in females may be enhanced as they shoulder the greatest burden of agricultural work and are less likely to own shoes than men. In Ethiopia, activities such as fetching water, cooking food, washing clothes, farming and buying goods from local markets are their daily duties and responsibilities. Podoconiosis is heavily affected the economically active

1 age group in this study. Studies in northern Ethiopia and Gulliso, West Wollega, have also
2 shown this age group to be strongly affected[5].

3
4 Episodes of ALA had been experienced in the past year by 88.8% of patients, a slightly lower
5 proportion than found in Gulliso *Woreda* (97%). Some patients linked ALA with “*chagino*” (the
6 time around the new moon, often associated in local understanding with weather changes). ALA
7 was not significantly associated with sex or age at onset of illness, consistent with the study in
8 West Wollega[5]. Activities were impaired by lymphoedema and ALA in about three-quarters of
9 patients. During ALA, patients experienced severe pain and had to stay in bed for several days.
10 A study conducted in northern Ethiopia showed that three in five patients claimed their
11 ‘movement’ was impaired by podoconiosis and one in four by ALA[16]. In this study, ALA
12 had considerably more impact on ability to work than previous studies. An average total of 150
13 days (five months) was lost by patients in Wayu Tuka *woreda* annually, six times that recorded
14 in Gulliso *woreda* (24 working days lost on average)[5]. Earlier studies showed that people with
15 podoconiosis were about half as productive as unaffected individuals, and that medical costs and
16 productivity losses exceeded US\$16 million per year in one zone (with population of 1.8 million)
17 in southern Ethiopia. According to this study, most patients did not completely stop work, but
18 spent only 3.56 ± 2.87 hours per day on economic activity compared to the 6.52 ± 2.53 hours
19 worked by controls. Female patients spent 3.45 hours less on domestic activity compared to
20 matched controls [10].
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34 One in four patients (25%) experienced stigma in this study. In contrast a study conducted in
35 northern Ethiopia showed that about 13% of patients had experienced one or more forms of
36 social stigma at school, church, or in the market place[16]. Stigma is increasingly being
37 recognized as an obstacle to good health and a barrier to accessing healthcare. Health-related
38 stigma affects the life chances of individuals, increasing their exposure to risks and limiting
39 access to protective factors, potentially adding to their burden of disease or disability[10,16]. The
40 main reasons for prevailing discrimination against patients and affected families are
41 the erroneous beliefs that podoconiosis cannot be prevented, treated or controlled; that it is
42 associated with curses; and that it runs in families through hereditary factors that make disease
43 inevitable[23,24].
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52 Most patients could reach a water source in an average 22-minutes walking round trip. Another
53 study in western Ethiopia also claimed that patients could access water with a walk of ‘only’
54 20minutes[5], however WHO defines access to drinking water as “availability of at least
55 20L/person/day/within 30 minutes’ walk’[25]. Patients may not have to walk far for water, but
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1 whether they can access adequate water is another question. Patients who wash their feet at least
2 once per day are less likely to experience ALA. In Wayu Tuka, 85% of patients washed their feet
3 at least once per day, a larger proportion than in Gulliso (66.7%[14]). However, a lower
4 proportion of patients used soap daily to wash their feet than in Gulliso (21.4% vs. 58%,
5 respectively). Using shoes regularly and washing feet with soap consistently was uncommon
6 among study subjects in Wayu Tuka *Woreda*. Our study showed there were several challenges to
7 primary and secondary prevention of podoconiosis. Inconsistent shoe-wearing was identified
8 among patients who owned shoes. Although few respondents were barefoot, the shoes they were
9 wearing (open plastic or open tyre) were not protecting them from irritant soil. The other issue
10 was the average age at which they started wearing shoes: at 25 years, this indicated prolonged
11 contact with soil and delay in protection.
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13 This study used a large scale community-based house to house survey in all *kebeles* of
14 Wayu Tuka *woreda*, followed by detailed study of podoconiosis patients. This provides a
15 complete profile of people with podoconiosis in the district. Nonetheless, the study is not without
16 limitations. A clinical algorithm was used to differentiate podoconiosis from other disease
17 causing leg swelling in such areas. Had a serological test been available, it would have helped
18 exclude lymphatic filariasis, the most common phenocopy in tropical areas. However, given that
19 the study area is at 2,200m above sea level, transmission of filaria is extremely unlikely.
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21 We recommend strong prevention and morbidity management interventions to address this
22 developmental challenge. These interventions will require collaboration between local
23 government and non-government stakeholders, and integration with existing programmes
24 addressing water and sanitation, neglected tropical diseases and chronic diseases.
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32 **Competing interests**

33 The authors declare that they have no competing interests.
34

35 **Authors' contributions**

36 KB designed the study, carried out data collection and prepared the first draft of the manuscript.
37 KD, GD, GT and AS revised study design. TA made field logistic arrangements. KB drafted the
38 manuscript. KD, GD and AS revised the manuscript. All authors read and approved the final
39 manuscript.
40

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3 (091956).
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7 **Data sharing statement:** No addition data are available.
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For peer review only

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Supplementary File 1

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract Done(Page1-2) (b) Provide in the abstract an informative and balanced summary of what was done and what was found Done
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported Done(Page 4)
Objectives	3	State specific objectives, including any prespecified hypotheses Done(Page 5)
Methods		
Study design	4	Present key elements of study design early in the paper Done(Page 5)
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection Done (page 5)
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants Done (Page 5)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable Done (Page 6)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group Done (page 5-6)
Bias	9	Describe any efforts to address potential sources of bias Done (Page 14)
Study size	10	Explain how the study size was arrived at Done (Page 6)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why Done (Page 6)
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding Done (page 6) (b) Describe any methods used to examine subgroups and interactions Done (Page 6) (c) Explain how missing data were addressed Not applicable (d) If applicable, describe analytical methods taking account of sampling strategy Done (Page 6) (e) Describe any sensitivity analyses Not applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed Done (Page 7) (b) Give reasons for non-participation at each stage Done (page 7) (c) Consider use of a flow diagram Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders Done (Page 7) (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures Done (Page 7)
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were

		adjusted for and why they were included Done (page 7-10)
		(b) Report category boundaries when continuous variables were categorized Done
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses Not applicable
Discussion		
Key results	18	Summarise key results with reference to study objectives Done(Page 12)
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias Done (Page 14)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence Done (Page 12-14)
Generalisability	21	Discuss the generalisability (external validity) of the study results Done
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based Done (page 15)

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

Supplementary File 2

Interviewer's name (HEW) _____ HEW code _____ sign. _____

Date ____/____/____

Registration Format (Wayu Tuka Woreda) Kebele _____ **'Zone'** _____

No	HH	HH mem	Do you know any patient With podoconiosis in your family?	How many?	First name	Fathers name	Sex 1.M 2.F	Age	Marital status
#	#	#	1 Yes2.No	#				#	#
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Detailed study**Kebele** _____ **Zone** _____ **Nurse** _____ **Nurse code** _____

Consent: we would like to ask you some questions to understand the problem of podoconiosis in your area. We also want to examine your legs .we hope that this will help plan services for people with this condition. Thank you for participating in this study.

1. REGISTRATION

1.1. Name _____ 1.2. Sex: 1.Male 2. Female 1.3.Age _____ years

1.4 .Number of years lived in this kebele _____ years

2. HISTORY OF DISEASE AND PERCEPTION ABOUT PODOCONIOSIS

2.1 How old were you (age) when you first noticed your legs are swollen? _____ Years

2.2 How long after the swelling you try to get treatment care? _____ Years

2.3 Where did you go first?

1. Health center
2. Health post
3. Hospital
4. Podoconiosis treatment center
5. Pharmacy/drug store
6. Traditional/healers
7. Others _____

2.4 When were you last sick with a painful swollen leg?

1. ____wks ago
2. ____months ago
3. ____years ago
4. Never (Go to Q 2.6)

INTERVIEWER: MAY I LOOK AT YOUR LEG?

2.5.1 Has the person got acute attack during the interview?

1. Yes
2. No (GO TO Q2.6.1)

2.5.2. If yes to Q2.5.1: what signs and symptoms do you observe?

1. Oozing
2. Tenderness (Pain in touch)
3. 3. Hot (on touch)
4. 4. Fever
5. 5. Swollen lymph node

2.6.1 Did you look for help?

1. Yes
2. No (GO TO Q2.6.3)

2.6.2. If 'YES' to Q2.6.1: where did you seek help?

1. Health center
2. Health post
3. Hospital
4. Podoconiosis treatment center
5. Pharmacy/ drug store
6. Traditional healers

2.6.3 Did you stay in bed?

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1. Yes

1. No (Go to Q2.6.5)

2.6.4 If “Yes” to Q2.6.3: How long you stay in bed? _____ days

2.6.5. How often in the last 12 months did you have this problem? ___times /every___months

2.6.6. Which time of the year is this problem worse?

1. All the time
2. Rainy season
3. Hot and dry season
4. During chagino
5. Others _____

2.6.7. What precipitate acute attack symptoms?

1. Hard (labours) work
2. A little more than usual work
3. Long walk
4. Other _____

2.6.8. How do you usually cope with (react towards) acute attack episodes?

1. Resort to less exertive work
2. Stay in bed
3. Other (specify) _____

PERCEPTION ON CAUSE, PREVENTION AND CONTROL OF PODOCONIOSIS

2.7. Why do you think you have podoconiosis? (NEVER READ ANSWERS.PROBE. CIRCLE ALL THAT APPLY)

1. I am barefooted
2. I or my families are cursed
3. This is a familial problem (it runs through ‘blood/ bone’ of our family)
4. I got it following contagion with an affected person (e.g. wore his/her shoes)
5. Following snake bite
6. Following exposure to condensation
7. I don’t know

2.9. Do you think podoconiosis can be prevented?

1. Yes
2. No - CIRCLE AND GO TO Q2.11
3. I don’t know(GO TO Q 2.11)

2.10 If the answer to Q2.9 was 'Yes': How can podocoinosis be prevented? (PLEASE DON'T READ THE ANSWERS. PROBE AND CIRCLE ALL THAT APPLY)

1. Wearing shoes protective of exposure to soil regularly
2. Washing feet with soap and water regularly
3. Avoiding marriage with affected families
4. Avoiding contact with affected

2.11. Do you think progression of podocoinosis can be controlled at early stages of the condition/is it curable?

1. Yes
2. No ...CIRCLE AND GO TO Q2.13
3. I don't know GO TO Q2.13

2.12. If the answer to Q 2.11 was 'Yes' how can podocoinosis be controlled at early stage? (PLEASE DON'T READ THE ANSWERS PROBE AND CIRCLE ALL THAT APPLY)

1. Wearing shoes protective of exposure to soil regularly
2. Washing feet with soap and water regularly
3. Avoiding marriage with affected families
4. Avoiding contact with affected

2.13. If the answer to Q2.12 was No: why do you think podocoinosis cannot be controlled (cured)? (PLEASE DON'T READ THE ANSWERS PROBE AND CIRCLE ALL THAT APPLY)

1. It is familial (runs through 'blood/bone')
2. There is no drug for it
3. I have never seen a cured person
4. Others specify _____

SOCIAL STIGMA

2.8. Did you experience any social stigma / discrimination because you have podocoinosis? (READ B-F ONE BY ONE. IF THEY ANSWER YES, UNDERLINE THE POINTS MENTIONED IN THE BRACKET. PROBE FOR OTHER EXPERIENCES PUT THAT UNDER 7)

1. No .people treat me like any person else.
2. Yes, schooling (drop out, shunning pointing fingers, pinching nose)
3. Yes, church (exclusion, shunning, pointing fingers, pinching nose)
4. Yes, marriage (exclusion, shunning, pointing fingers, pinching nose)
5. Yes, market place (people are not interested to buy my products)

6. Yes, feasts (exclusion, shunning, pointing fingers, pinching nose)

7. Others (specify) _____

2.14 Examination

	2.14.1 stage 1-5	2.14.2 mossy 1. Yes 2. No	2.14.3 wound 1. Yes 2. No	2.14.4 type(watery, bag, nodular, mixed)	2.14.5 Greatest below knee leg circumference (cm)
1. right leg					
2. left leg					

3. BACKGROUND

3.11. Educational status:

1. cannot read and write
2. Read and write

3.12. If the answer to Q 3.11 is (2) what grade are you? _____

3.2 Main occupation

1. Farming
2. Weaving
3. Daily labourer
4. House
5. Others _____

3.3. Marital status

1. Single.
2. Married
3. Widowed
4. Divorced
5. Separated

3.4. FAMILY HISTORY

(NOTE: THIS PART IS A VERY SENSITIVE, YET RELEVANT SECTION. SO YOU SHOULD BE EXTRA POLITE AND EXPLAIN THAT ALL INFORMATION WILL BE KEPT CONFIDENTIAL. IN ADDITION MENTION THAT THIS INFORMATION WILL BE RELEVANT FOR TARGETING DISEASE PREVENTION AND TREATMENT PROGRAMS)

3.4.1. Does any member of your family (meaning relatives such as parents, grandparents, cousins, siblings, or children) have podoconiosis?

1. Yes
2. No _____ GO TO Q3.4.3

3.4.2 If “Yes” to Q3.4.1: how are you related? (PROBE FOR OTHER CATEGORIES)

	a. #	b. sex 1.M 2.F	Still alive? 1. Y 2. N
3.4.2.1 Grandparent?			
3.4.2.2 parent?			
3.4.2.3 sibling?			
3.4.2.4 child?			
3.4.2.5 other?			

3.4.3 How many member of your household (together with you) are affected? _____

3.4.4 Is that person available for interview? 1. Yes 2. No

NOTE TO INTERVIEWER: IF THE ANSWER IS “YES”, RECORD THE FOLLOWING AND GIVE APPOINTMENT FOR NEXT DAY INTERVIEW BY A NURSE.

Name _____ Age _____ Sex 1. Male 2. Female

3.4.5.1 Are any children in the house complaining of problems with feet? 1. Yes 2. No

3.4.5.2 If Yes to Q3.4.5.1: what are the signs and symptoms?

NOTE TO INTERVIEWER: IF THE ANSWER IS “YES”, RECORD THE FOLLOWING AND GIVE APPOINTMENT FOR NEXT DAY INTERVIEW BY A NURSE.

Name _____ Age _____ Sex 1. Male 2. Female

3.4.6 Why do you think there are multiple affected family members in your

Family (household)? (CIRCLE ALL ANSWERS SPECIFIED)

1. Because the disease is contagious
2. Because the disease runs through families (blood/ bone)
3. Because the family is cursed/ any spiritual connection
4. Because the family is poor and cannot afford shoes
5. I don't know
6. Others specify
- 7.

4. WEARING SHOES

4.1.1. How old were you when you first got shoes? _____ Years

4.1.2 How old were you when you first got shoes? _____ Years

4.2 interviewers: observe and describe the shoes the person is now wearing.

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1. Hard plastic open
 2. Hard plastic covered
 3. 'Barabaso'
 4. Leather
 5. 'Shara'/canvass
 6. Bare footed

4.3. When you usually not wear shoes?

1. During farming
2. During Non –Farming Work
3. At Home
4. I Am Usually Bare Footed
5. I Am Always Barefooted

4.4. How many pairs of shoes do you have? _____

4.5. How many pairs of shoes do you need / year? _____

5. WASHING FEET

5.1 can you get enough water?

1. Yes (go to q 5.3)
2. No

5.2 If no q5.1: what was the problem?

1. Seasonal shortage
2. Distance
3. Others specify_____

5.3. How long (in minutes) do you go to the nearest water source (1 way)? _____ Minutes

5.4. Did you wash your feet last night?

1. Yes
2. No

5.5 If yes to q5.4. Interviewer: please observe and describe the cleanliness of the feet

1. Clean and intact
2. Dirty
3. Cracked
4. Dirty and cracked

5.6 How many times do you wash your feet? _____ Times

5.7. After your feet started swelling, did your foot washing behaviours changed?

1. Yes
2. No (go to q 5.9)

5.8. If yes to q5.7: do you wash your feet more often / less often?

1. More often
2. Less often

5.9. Do you use soap for your feet?

1. Yes
2. No

5.10. If “yes” to q5.6: how many times/ times do you wash your feet with soap? _____times

DISTANCE WALKED

6.1. How long does it take to go to your nearest field? _____min/hrs

6.2. How many times do you go to your field each month? _____times

6.3. How long does it take to go to your nearest market month? _____minutes

6.4. How often do you go to market each month? _____times

6.5. ASK ANOTHER PERSON OF THE HOUSEHOLD: How many times last year was the person sick with acute attack? _____

7. DISABLING EFFECTS (FUNCTIONAL IMPAIRMENT)

7.1. Over the past 30 days, has podoconiosis or acute attack of ALA hampered movement (walking, travelling to markets etc) (MORE ONE ANSWER POSSIBLE)

1. Yes, effect of the disease
2. Yes effect of acute attacks
3. Uncertain
4. No

7.2. ASK WOMEN: over the past 30 days, has podoconiosis or acute attack of ALA hampered any house hold chores (cleaning, cooking, child care etc) (MORE THAN ONE ANSWERS POSSIBLE)

1. Yes, effect of the disease
2. Yes effect of acute attacks
3. Uncertain
4. Not applicable (circle this if the respondent is a man)

7.3. ASK MEN: Over the past 30 days, has podoconiosis or acute attack of ALA hampered daily/ occupational work? (MORE THAN ONE ANSWER IS POSSIBLE)

1. Yes, effect of the disease

2. Yes effect of acute attacks
3. Uncertain 4. not applicable (if a woman)

7.4. If either 7.2 or 7.3 is 'yes': what was the effect of the disease? (Read each answer & circle all that apply)

1. Work less hours
2. Worked less energy
3. Absence from work
4. Earned less income
5. Reduced productivity (e.g. harvest from agriculture)
6. Others (specify) _____

7.5. How has podoconiosis affected your work life over a long period of time (many months or years)? (Read each answer and circle all that apply)

1. I work only occasional
2. I work less hours
3. I restored to less remunerative work
4. I avoided physically demanding tasks
5. I totally stopped work
6. Other _____

7.6. How do you rate your financial status compared to your fellow neighbours with the same occupation and family size?

1. About the same
2. I am poorer
3. I am better off

7.7. If the answer to q 7.6 was '2': did your financial status worsen after your family became affected by podoconiosis?

1. Yes
2. No

We have finished the interview. Thank you for time and participation!

Appendix 2: Standard Training Material Used To Train Nurses and HEWs

Podoconiosis: Differential Diagnosis, & Clinical Staging (Professor G. Davey)

Differential diagnosis - which other conditions could it be?

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1• Filarial Lymphoedema

3• Leprosy

2• Onchocerciasis

4• deep fungal infection

1. Filarial lymphoedema

Ask: Is patient from lowland area? Did the swelling start at the foot or higher up?

Look: Is leg swelling very asymmetrical (one leg 'normal')?

Examine: Check the groin for swollen lymph node

Do: Refer for tablet treatment at Health Centre, invite back for usual MFTPA leg care.

2. Onchocerciasis

Ask: Does patient have itchy trunk or nodules?

Look: Look for onchodermatitis, pretibial depigmentation, onchocercomas, eye changes

Examine: Examine skin of whole body, check the groin for lymph nodes

Do: Refer for treatment of onchocerciasis, invite back for usual MFTPA leg care.

3. Leprosy

- Exaggerated eyebrow area
- Shiny skin on feet
- Toes may look short
- Foot ulcer may be present
- Patient cannot feel

Ask: Has the patient noticed any skin changes?

Look: Are there rough raised skin lesions?

Examine: For thickened nerves at the elbow or behind the ear; for foot ulcers; check if patient can feel you touch his feet?

Do: Refer for leprosy treatment. Invite back for follow up MFTPA foot care.

5. Fungal

Deep fungal infection Lump on one foot May have small black dots on surface

Do: Refer to surgeon for biopsy, anti-fungal treatment/amputation

CLINICAL STAGING

Why is staging important?

- So program planners can assess burden of disease in given area;

- So patients can see effect of self-treatment;
- So health professionals can document effectiveness of medical and surgical treatment;
- So researchers can document effects of public health interventions.

Stage 0. No disease present.

Stage 1. Swelling reversible overnight.

Stage 2. Persistent below-knee swelling; if present, knobs or bumps are below the ankle ONLY

Stage 3. Persistent below-knee swelling; knobs or bumps present above the ankle.

Stage 4 . Persistent above-knee swelling; knobs or bumps present at any location.

Stage 5. Joint fixation; swelling at any place in the foot or leg. (X-rays may show tuft erosion and loss of bone density)