

# Individual and familial characteristics of patients with podoconiosis attending a clinic in Musanze District, Rwanda: A retrospective study

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**Background:** Podoconiosis is a progressive swelling of the legs affecting genetically susceptible people who live in areas with irritant red clay soils and walk barefoot. The disease is a public health concern in many countries, including Rwanda.

**Methods:** This retrospective study described individual and familial characteristics of patients with podoconiosis attending the Heart and Sole Africa (HASA) clinics in Rwanda. Data on patient characteristics and family history were retrieved from electronic medical records (January 2013 – August 2019). A multiple regression analysis was used to explore factors influencing age of onset of podoconiosis.

**Results:** Among 467 patients with podoconiosis, the mean (standard deviation) age of onset was 34.4 (19.6) years, 139 (29.8%) patients developed podoconiosis at <20 years of age, 417 (89%) came from Musanze or neighboring Burera Districts, and 238 (51.0%) had a family history of podoconiosis. Increasing patient age was associated with older age at onset of disease ( $p < 0.001$ ), while an increased number of relatives with podoconiosis ( $p < 0.002$ ) was significantly associated with earlier disease onset.

**Conclusion:** Most patients with podoconiosis were women, and more than half had a family history of podoconiosis. An increased number of relatives with podoconiosis was associated with a significantly younger age at disease onset.

**Keywords:** access to healthcare, age of onset, epidemiology, family history, podoconiosis, Rwanda

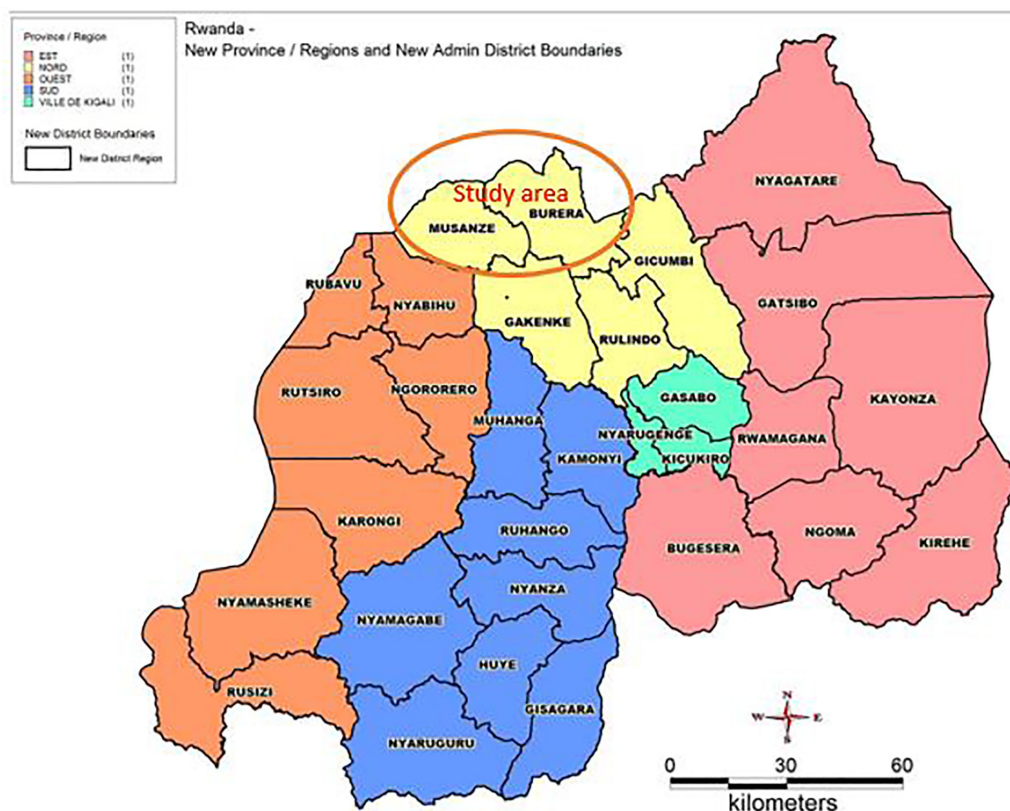
## Introduction

Podoconiosis (also known as non-filarial elephantiasis) is a non-infectious elephantiasis that affects subsistence farmers who walk barefoot on irritant red clay soils for a prolonged period,<sup>1</sup> and who are genetically susceptible.<sup>2</sup> The condition results in inflammation of lymphatic vessels, which progressively causes swelling of the legs and feet.<sup>2</sup>

Podoconiosis has been found in 17 countries, mostly in the tropics.<sup>3</sup> Globally, it is estimated that 4 million people are disabled due to podoconiosis.<sup>2</sup> The disease is highly stigmatizing, reduces the quality of life and productivity of the affected individual, and causes depression.<sup>4</sup> Affected people are avoided at community gatherings and shamed in public, leading to low quality of life

and mental distress.<sup>5,6</sup> Additionally, due to frequent episodes of illness, patients lose many hours of work and suffer an increased healthcare burden; in Ethiopia, in 2017, 1.5 million cases of podoconiosis corresponded to 172 073 disability-adjusted life years.<sup>7</sup> Although the disease is associated with a considerable health burden and socioeconomic consequences, interventions appropriate for podoconiosis are not widely available, even in endemic countries.<sup>8–10</sup>

Recent nationwide mapping revealed that podoconiosis cases were distributed in all 30 districts of Rwanda, with national prevalence of 68.5 per 100 000 population.<sup>4</sup> However, beyond the prevalence and distribution information from the national mapping, little is known about the individual characteristics



**Figure 1.** Map of Rwanda showing administrative districts. Source: [https://commons.wikimedia.org/wiki/File:Rwanda\\_Districts\\_Map.jpg](https://commons.wikimedia.org/wiki/File:Rwanda_Districts_Map.jpg) (accessed 14 May 2020). This artwork is free to redistribute and/or modify according to terms of the Free Art License from Copyleft Attitude.

and family history of patients with podoconiosis or factors that influence the age of onset of the disease.

Currently, one organization called Heart and Sole Africa (HASA) provides treatment to patients with podoconiosis in Rwanda. HASA is a non-profit organization located in Musanze District, Rwanda, whose vision it is to eliminate podoconiosis nationally. The organization currently has 528 registered patients from different areas across the country. Diagnosis of podoconiosis at HASA is based on history, observation and clinical information (bilateral swelling but with asymmetric onset, and limited below the knee).<sup>11</sup> It is important to understand the factors that influence age of onset of podoconiosis in order to be able to plan timely intervention strategies to prevent or reduce the onset of the disease.

The objectives of this study were to describe the basic individual characteristics and family history of patients with podoconiosis attending a HASA podoconiosis clinic in Musanze District, and to determine the factors that influence the age of onset of podoconiosis.

## Materials and methods

### Study setting

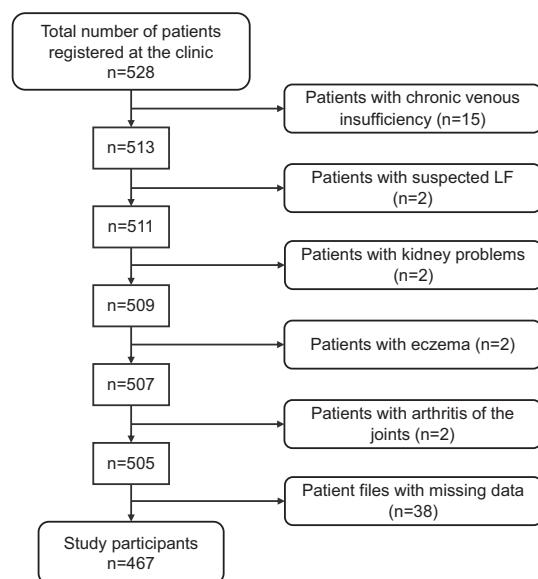
Rwanda, situated in East Africa, has a population of approximately 12 374 397 million and covers a geographic area of

26 338 square kilometers.<sup>12</sup> It is a mountainous country that has five volcanoes and has annual rainfall of between 1000 and 1400 mm.<sup>13</sup> Previous studies found volcanic soils<sup>14</sup> and annual rainfall above 1000 mm<sup>15</sup> to be associated with risk of podoconiosis. The majority of Rwanda's inhabitants (91.1%) are subsistence farmers.<sup>16</sup> Rwanda is divided into four provinces and the capital city Kigali, which are further divided into 30 administrative districts (Figure 1).

### Study design and patient population

This retrospective study analyzed data from patient files at two HASA podoconiosis clinics: the main clinic located in Musanze District, and a satellite clinic in Burera District.

Patient's data were retrieved from electronic medical records from January 2013 to August 2019 and entered into Microsoft Excel for data cleaning (i.e. adjusting and modifying data for analysis). Complete data on age, gender, district, pain status, family history of podoconiosis, number of relatives with podoconiosis, relationship of family members with podoconiosis and age of onset of podoconiosis were collected. This information is collected for every patient at the time of their first visit to a HASA clinic. The relationship of relatives with podoconiosis was categorized as immediate family member (i.e. parent, grandparent or sibling) or extended family member (i.e. uncle, aunt or cousin).



**Figure 2.** Clinical algorithm for selection of patients with podoconiosis, attending clinic in Musanze and Burera Districts, Rwanda from 2013 to 2019, for inclusion in the study.

Patient files with missing data for one or all of the above-mentioned variables were not included in this study. Data from patients with other conditions like chronic venous insufficiency, eczema, suspected lymphatic filariasis and joint arthritis were not considered for this study (Figure 2).

Permission to use the dataset was obtained from HASA administrative leaders. On their first clinic visit, each patient verbally agreed to answer brief questions related to podoconiosis once assured that the information provided would be kept confidential and used only to serve the purpose of the organization.

## Data analysis

Patient data were imported into STATA version 13.0 (College station, Texas 77 845, USA) and summarized in tables and graphs. Descriptive statistics (means and standard deviations [SD] for continuous variables and frequencies for categorical variables) were used. A bivariate analysis was carried out and all variables with  $p$ -value  $<0.05$  were included in the multiple regression analysis.

A multiple regression analysis was performed to determine the factors influencing age at onset of podoconiosis. Categorical variables were recoded and transformed into dichotomous data with value 1 or 0 to be entered in the regression analysis, where 1 indicated presence of characteristics and 0 indicated their absence. A  $p$ -value  $<0.05$  was considered to be statistically significant.

## Results

### Characteristics of patients with podoconiosis

Complete data were available for 467 patients who attended the clinic from January 2013 to August 2019. Of these, 375 (80.3%)

**Table 1.** Characteristics of patients with podoconiosis (N=467) attending Heart and Sole Africa Clinics in Musanze and Burera Districts, Rwanda from 2013 to 2019

Variable	Category	Number (%) patients*
Gender	Male	92 (19.7)
	Female	375 (80.3)
Occupation	Farmers	441 (94.4)
	Students	21 (4.5)
	Businessman/woman	2 (0.4)
	Public servant	3 (0.6)
Pain	No	30 (6.4)
	Yes	437 (93.6)

\* Percentages may not add up to 100 due to rounding.

were female and the male to female ratio was 1:4.1 (Table 1). Most patients ( $n=441$ , 94.4%) were farmers, 21 (4.5%) were students, two (0.4%) were traders and three (0.7%) were public servants (Table 1).

The mean (SD) age of the patients was 51.9 (20) years (range 9–94 years). More than a half (270 [57.8%]) of patients were  $\geq 50$  years of age and the largest age group was 60–69 years (95; 20.3%) (Figure 3A). The mean (SD) age of onset of podoconiosis was 34.4 (19.6) years (range 4–83 years). After categorizing the age of onset, 139 (29.8%) patients developed the disease when aged  $\leq 19$  years (Figure 3B). Almost all patients (93.6%) reported pain of the feet and legs (Table 1).

Most patients, 254 (54.4%), were from Musanze District and 163 (34.9%) were from adjoining Burera District (Figure 4).

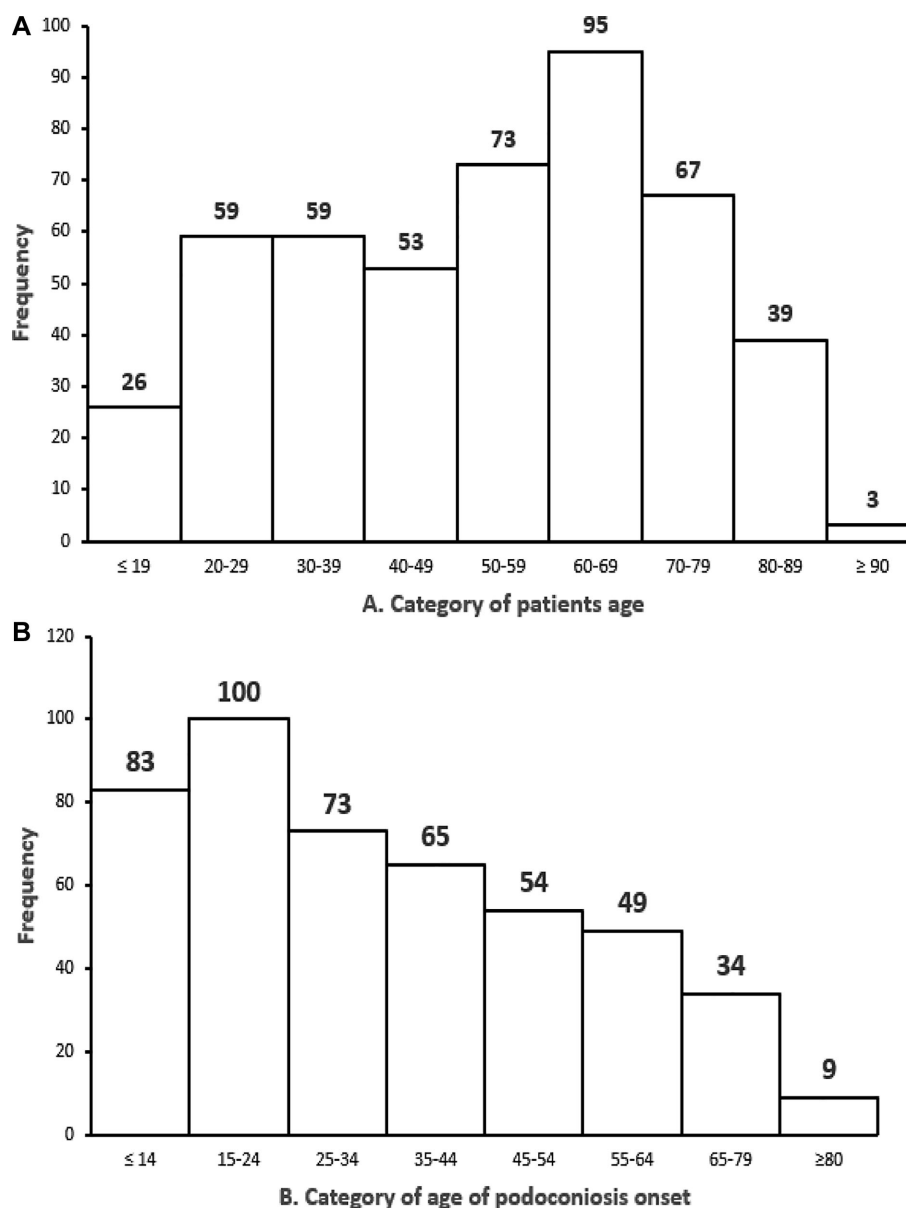
### Family history of patients with podoconiosis

Of the 467 patients included in the study, 238 (51.0%) had one or more relatives who had podoconiosis, while 221 (47.3%) reported that they did not have a family history of podoconiosis (Table 2). Only eight (1.7%) patients did not know their family history with regards to podoconiosis.

Of the 238 patients with a family history of podoconiosis, 181 (76.1%) reported that they had one affected relative, while 57 (23.9%) had more than one affected family member (Table 2). The mean (SD) number of relatives affected by podoconiosis per family was 1.3 (0.65; range 1–5).

Among patients with a family history of podoconiosis, 226 (94.9%) gave details on their relationship with a family member with podoconiosis (Table 2). Of these, 177 (78.3%) said they had immediate family members affected with the disease, while 33 (14.6%) had extended family members affected (Table 2). A small proportion of patients (7.1%) reported having both immediate and extended family members affected by podoconiosis.

The mean (SD) age of podoconiosis onset was 32.9 (17.9) years among those with only one person affected in the family and 27.5 (16.8) years for those with two or more affected family members.



**Figure 3.** Histogram showing (A) patient age and (B) age at onset of podoconiosis among patients with podoconiosis (N=467) attending Heart and Sole Africa clinics in Musanze and Burera Districts, Rwanda from 2013 to 2019.

### Factors influencing age of onset of podoconiosis

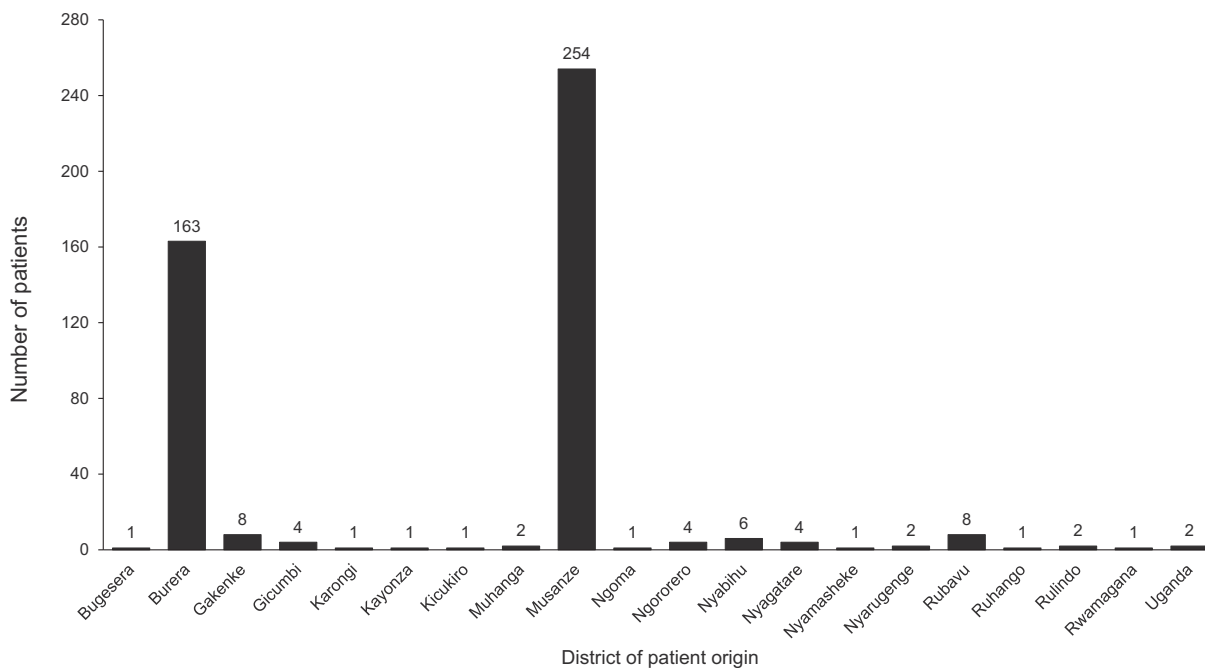
In the bivariate analysis, patient age ( $p < 0.001$ ), occupation ( $p < 0.001$ ) and family history ( $p = 0.026$ ) of podoconiosis were found to be significantly associated with the age of onset of podoconiosis (Table 3). Gender and relationship of family members with podoconiosis had no significant effect.

Variables that were statistically significant in the bivariate analysis (age, occupation and family history) were included in multiple regression model (Table 4). The model explained 60.9% ( $R^2 = 0.609$ ) of variation in age of onset of podoconiosis:  $F(5, 232) = 72.34$ ;  $p < 0.001$ . Patient age was significantly associated with an increased age of onset of podoconiosis:  $\beta = 0.78$ ,  $p < 0.001$  (95% CI 0.63, 0.78), while an increased number of relatives with

podoconiosis was associated with a younger age of onset of podoconiosis:  $\beta = -0.14$ ;  $p = 0.002$  (95% CI  $-6, -1.5$ ) and regression coefficient was  $-3.9$  (Table 4).

### Discussion

This study describes basic individual characteristics and familial history among patients who attended HASA podoconiosis clinics in Musanze and Burera Districts, Rwanda. Most patients (80.3%) were women and more than half (51.8%) had a family history of podoconiosis. Increased patient age was associated with older age at onset of podoconiosis, while an increased number of



**Figure 4.** Districts of origin for patients with podoconiosis attending Heart and Sole Africa clinics in Musanze and Burera Districts, Rwanda from 2013 to 2019.

**Table 2.** Family history of podoconiosis among patients with podoconiosis (N=467) attending the Heart and Sole Africa clinics in Musanze and Burera Districts, Rwanda from 2013 to 2019

Variable	Category	Number (%) patients
Family history of podoconiosis (N=467)	No	221 (47.3)
	Yes	238 (51.0)
	Not known <sup>a</sup>	8 (1.7)
Number of relatives with podoconiosis (n=238)	1	181 (76.1)
	≥2	57 (23.9)
Relationship of family members with podoconiosis (n=226)	Immediate family members <sup>b</sup>	177 (78.3)
	Extended family members <sup>c</sup>	33 (14.6)
	Both immediate and extended family members	16 (7.1)

<sup>a</sup>Patient did not know their family history with regards to podoconiosis.

<sup>b</sup>Immediate family member = parent, grandparent or sibling.

<sup>c</sup>Extended family member = uncle, aunt or cousin.

relatives affected by podoconiosis was associated with a significantly younger age at disease onset.

Our findings are similar to those of a previous nationwide mapping of podoconiosis in Rwanda, which found that women were almost twice as likely to be affected by the disease with a prevalence of 89 per 100 000 population compared with 43 per 100 000 population for men.<sup>4</sup> Nationwide mapping in Ethiopia also found that women were more likely to be affected than men, with a male to female ratio of 0.7:1.<sup>17</sup> In contrast, mapping conducted in Cameroon observed that the prevalence was slightly higher among men than women (0.99% and 0.68%,

respectively).<sup>18</sup> One possible explanation may be lack of access to healthcare services. Alternatively, cultural and social norms may mean that men seek healthcare services less frequently than women.<sup>19,20</sup> Lastly, it is more common in Rwanda for men to wear closed shoes that better protect the feet from dust while women are more likely to wear open shoes (e.g. sandals).

In this study, the mean age of patients with podoconiosis was 51.9 years and the majority of patients (57.8%) were aged ≥50 years. This is very similar to the findings of the nationwide mapping, which showed that the majority of patients (68%) were



**Table 3.** Bivariate regression analysis showing the influence of patient characteristics and family history on age of onset of podoconiosis among patients (N=467) attending the Heart and Sole Africa clinics in Musanze and Burera DISTRICTS, Rwanda from 2013 to 2019

Variable	Coefficients	p value	95% CI	$\beta$
Age	0.8	<0.001	0.7, 0.9	0.81
Gender				
Female	Reference			
Male	1.5	0.51	-6, 3	0.03
Occupation				
Farmer	Reference			
Student	-22.8	<0.001	-31.1, -14.4	-0.24
Business	-16.6	0.21	-43.1, 9.9	-0.05
Public servant	-14.6	0.18	-36.2, 7.0	-0.06
Number of relatives	-3.9	0.026	-7.5, -0.5	-0.15
Relationship of affected family member				
Immediate <sup>a</sup>	Reference			
Extended <sup>b</sup>	-3.5	0.29	-10.0, 3.0	-0.07
Both	-5.8	0.2	-14.8, 3.13	-0.85

$\beta$ : beta; CI: confidence interval at the significance level of 5%.

<sup>a</sup>Immediate family member = parent, grandparent or sibling.

<sup>b</sup>Extended family member = uncle, aunt or cousin.

Linear regression was performed for all variables after the categorical variables had been transformed as dichotomous data.

**Table 4.** Multiple regression analysis showing the influence of patient characteristics and family history on age of onset of podoconiosis among patients (N=467) attending the Heart and Sole Africa clinics in Musanze and Burera Districts, Rwanda from 2013 to 2019

Variable	Coefficient	p value	95% CI	$\beta$
Age	0.8	<0.001	0.63, 0.79	0.78
Occupation				
Farmer	Reference			
Student	3.2	0.37	-0.3.8, 10.2	0.04
Business	-2.8	0.73	-18, 13	-0.01
Public servant	14.8	0.22	-8.6, 37.5	0.05
Number of relatives	-3.9	0.002	-6, -1.5	-0.14

$\beta$ : beta; CI: confidence interval at the significance level of 5%.

aged above 45 years and that prevalence of the disease increases with age.<sup>4</sup>

The mean (SD) age of onset of podoconiosis was 34.4 (19.6) years. This represents the middle of the most active and productive working age (18–64 years). Our findings showed that the majority of patients developed podoconiosis at an age of <20 years, slightly earlier than the age of onset in Ethiopia, where the majority of patients develop the disease between 20 and 30 years old.<sup>21</sup> Although patients' ability to recall exactly when the disease started may be questionable, disease onset in the second or third decades of life seems to be the norm, reinforcing the

importance of prevention measures during the years of exposure in childhood and adolescence.

More than half (54.4%) of patients were from Musanze District, while 34.9% came from the adjacent district, Burera. Because of travel difficulties, only patients close to the western border of Burera were able to benefit from HASA clinic services. Patients from other districts barely accessed the HASA podoconiosis clinic. Only one patient from Nyamasheke District (which does not adjoin Musanze District) was able to attend the clinic, even though Nyamasheke has the highest district prevalence, at 119.3 per 100 000 population.<sup>4</sup> Similar to our findings, long travel distances or lack of availability of treatment sites were reported to be major barriers to accessing and continuing treatment in Ethiopia.<sup>8,9</sup>

Given there is currently no state health facility providing care for patients with podoconiosis in Rwanda, these findings imply that there is an urgent need to expand and integrate podoconiosis services into the existing health system in other parts of the country. This should begin with the highest prevalence districts, e.g. Nyamasheke and Rusizi in West Province.

Genetic research on podoconiosis conducted in Ethiopia shows that the disease runs in families, with siblings of patients at 5.07 times the risk of developing podoconiosis compared with the general population.<sup>22</sup> Our findings show that more than half (51.0%) of patients treated at the clinic had a family history of podoconiosis and between one and five affected relatives. This was slightly higher than the proportion of participants reporting relatives with podoconiosis from previous studies in Ethiopia (38%,<sup>23</sup> 34%<sup>24</sup> and 30%).<sup>25</sup> This difference may be explained by the ability of participants to recall family history, or by differences in methodology between the studies.

The present study demonstrated a strong relationship between patient age and age of onset of the disease. Age of onset increased as age of the affected individual increased ( $p<0.001$ ; 95% CI 0.63, 0.79; regression coefficient=0.8). This finding may be explained by the fact that the disease develops among those who have more years of exposure to irritant soils. However, among patients with a family history of podoconiosis, those with a greater number of relatives with podoconiosis developed the disease at a younger age than those without, or with fewer, affected relatives. The age of onset of podoconiosis development dropped by 3.9 years of age as the number of affected relatives increased by one ( $p=0.002$ ; 95% CI -6, -1.5,  $\beta=0.14$ ).

The study was limited to patient information recorded at the clinic, which did not provide details on family pedigrees. Although patients were asked at their first visit how many of their family members had podoconiosis, patients could not recall exactly the number of relatives who had had podoconiosis from current or previous generations. This may have caused an underestimation in the number of family members with podoconiosis. A cross-sectional study to include socioeconomic factors could be conducted with a greater emphasis on obtaining the family tree details for several generations.

## Conclusion

This study documented the individual characteristics and family history of patients with podoconiosis, and the factors that might influence the age of onset of podoconiosis. We

demonstrated that age of onset of podoconiosis increases with increasing patient age and decreases as the number of relatives affected by podoconiosis increases, regardless of family relationship (i.e. immediate or extended family members, or both). Thus, we recommend that the Rwanda Ministry of Health and Ministry of Gender and Family Promotion should instigate health education programs to prevent podoconiosis, with special attention given to affected families while trying to avoid any potential increase in stigma that this might bring. Efforts must be made to encourage and support communities in the use of preventive footwear and the practice of foot hygiene, so that the next generation grows up free from podoconiosis. Monthly community work known as Umuganda, parents' evening dialogue, regular community meetings and churches may be used to convey this information to these families.

**Authors' contributions:** JPB designed the study protocol, conducted the data analysis and critical discussion of the data and prepared the first draft of the manuscript. JPB and MJD extracted data from patients' electronic files. GD revised the manuscript for intellectual content and scientific format, and provided access to important relevant literature. UB, TH, ER, MJD, JBM and GD critically reviewed and revised the manuscript for intellectual content at all stages of development. All authors read and approved the final manuscript. JPB and GD are guarantors of the paper.

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**Ethical approval:** Not required.

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