

# An exploration of family quality of life in persons with leprosy-, lymphatic filariasis- and podoconiosis-related disabilities and their family members in Ethiopia

Anna T. van't Noordende <sup>a,b,c,†</sup>, Moges Wubie Aychew <sup>d,\*,†</sup>, and Alice P. Schippers <sup>a,e</sup>

<sup>a</sup>Programme Department, Stichting Disability Studies in Nederland, p/a Marelaan 61, 3454 GB De Meern, The Netherlands; <sup>b</sup>Technical Department, NLR, Wibautstraat 137K, 1097 DN Amsterdam, The Netherlands; <sup>c</sup>Department of Public Health, Erasmus Medical Center, University Medical Center Rotterdam, Doctor Molewaterplein 40, 3015 GD Rotterdam, The Netherlands; <sup>d</sup>Department of Public Health, Debre Markos University, A3, Debre Markos, Ethiopia; <sup>e</sup>Amsterdam University Medical Centre, VU Medical Center, De Boelelaan 1117-1118, 1081 HV Amsterdam, The Netherlands

\*Corresponding author: Tel: +251 91 207 6152; E-mail: [mogeswub@gmail.com](mailto:mogeswub@gmail.com)

<sup>†</sup>These authors contributed equally to this work.

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**Background:** Leprosy, podoconiosis and lymphatic filariasis (LF) may adversely affect the social, economic and psychological well-being of persons affected and their families. The objectives of this study were to assess and compare family quality of life of persons affected and their family members, explore the relationship between family quality of life and perceived stigma and activity limitations and explore what factors influence family quality of life.

**Methods:** A cross-sectional quantitative study was conducted in the Awi zone in Ethiopia. Persons affected and their family members were selected using purposive sampling. Three questionnaires were used: the Beach Center Family Quality of Life (FQOL) scale (range 25–125, with higher scores denoting higher family quality of life), the SARI Stigma Scale (range 0–63, with higher scores denoting higher levels of stigma) and the Screening of Activity Limitation and Safety Awareness (SALSA) scale (range 0–80, with higher scores denoting more activity limitations). Data analysis consisted of simple descriptive analysis and regression analysis.

**Results:** A total of 95 persons affected and 117 family members were included. The overall mean of the family quality of life score was 71.7. Persons affected had significantly higher mean family quality of life scores than family members on all domains. Female gender, a smaller family size and occupation were associated with lower family quality of life. We found a mean SARI Stigma score of 22.3 and a mean SALSA score of 37.6. There was no association between the FQOL and SARI scores or between the FQOL and SALSA scores.

**Conclusions:** Family quality of life is an important area to address because neglected tropical diseases often affect the whole family. It is therefore important in order to provide appropriate support for persons affected and their family members. Efforts to improve the quality of life of families in which a family member is affected by leprosy, podoconiosis or LF should give priority to women and families with a smaller family size.

**Keywords:** disability, leprosy, lymphatic filariasis, podoconiosis, stigma, quality of life

## Introduction

Leprosy is one of the oldest known diseases.<sup>1</sup> It is a chronic infectious disease caused by *Mycobacterium leprae*. Leprosy primarily affects the peripheral nerves, mucosal surfaces of the respiratory tract and skin of human beings.<sup>2</sup> Lymphatic filariasis (LF) is an infectious disease caused by three species of filarial worm: *Wuchereria bancrofti*, *Brugia malayi* and *Brugia timori*. The disease

is transmitted via the bite of an infected mosquito.<sup>3</sup> Inflammation and lymphoedema in LF can lead to damage of the lymph nodes and swelling and enlargement of the legs, arms, genitals, vulva and breasts.<sup>4</sup> Podoconiosis is non-filarial lymphoedema of the lower limb. It affects genetically susceptible individuals who are exposed to red clay soil for a long period of time.<sup>5</sup> Leprosy, LF and podoconiosis are neglected tropical diseases (NTDs).<sup>6</sup> All three conditions are endemic in Ethiopia.<sup>7–9</sup>

All three conditions can lead to temporary and permanent physical impairments.<sup>10-12</sup> These impairments may adversely affect the social, economic and psychological well-being of persons affected by the disease.<sup>13-16</sup> In addition, these impairments can cause limitations of functional activities involving use of legs (podoconiosis and LF)<sup>5</sup> and hands, feet and eyes (leprosy).<sup>17,18</sup> Predominantly because of pain and functional limitations, persons affected may not be able to properly or fully work.<sup>16,19-23</sup> In addition, pain, impairments and social stigma may cause difficulties in getting a job for persons affected.<sup>19,24,25</sup> Being affected by one of these conditions thus significantly contributes to poverty among those affected.

Persons affected by leprosy, LF and podoconiosis are often stigmatized.<sup>21,23,26-28</sup> This may result in restrictions in social participation, such as isolation and barriers to education or marriage.<sup>14,21,23,28</sup> Family members may also experience stigma and discrimination because of the affected family member.<sup>29-31</sup> At the same time, family members may also be a source of discrimination.<sup>24,25</sup> The quality of life of those directly and indirectly affected by these diseases may be negatively affected.<sup>32-34</sup> Except for a recently published qualitative exploration, no study has been conducted on the impact of these conditions on family quality of life.<sup>34</sup> Where individual quality of life, which is closely linked to well-being, broadly encompasses an individual's perception of how 'good' several aspects of their life are, family quality of life is focused on all family members in the family unit rather than on individuals.<sup>35,36</sup>

Leprosy, podoconiosis and LF have a considerable social and economic impact on those affected by these conditions. Persons affected may experience physical impairments, functional activity limitations, social participation restrictions and social stigma and discrimination.<sup>17</sup> These negative consequences can have an adverse effect on quality of life.<sup>22,24</sup> Understanding the relationship between (family) quality of life, perceived stigma and activities can help us establish the full burden of these conditions and can help in the development of appropriate services and in monitoring, evaluation and advocacy. The objectives of this study are to assess and compare the family quality of life of persons affected and their family members, explore the relationship between family quality of life and perceived stigma and activity limitations and explore what factors influence family quality of life. This study is part of a larger project that aims to develop a family-based intervention for prevention and self-management of leprosy-, podoconiosis- and LF-related disabilities in Ethiopia.

## Materials and methods

### Study design

We used a cross-sectional study design with a quantitative approach. Interview-administered questionnaires were used to assess stigma and activity levels of persons affected and family quality of life of persons affected and their family members.

### Study site

The study was conducted in northwest Ethiopia, in the Awi zone. The Awi zone is one of the 13 zones in the Amhara

region. There are seven different *woredas* (districts) in the Awi zone and our study was conducted in three of them: Guangua (Zigem), Guagusa Shikudad (Injibara town) and Fagita Lekoma (Addis Kidam town). Podoconiosis and LF are mainly endemic in Zigem,<sup>37</sup> while leprosy is endemic in Injibara and Addis Kidam.<sup>38</sup> Almost all inhabitants of the Awi zone (94%) practice Orthodox Christianity.<sup>39</sup>

### Study population and sample

We included persons affected by leprosy, LF and podoconiosis and family members of the persons affected. Since this study was part of a study that aimed to develop and pilot an intervention, we calculated the sample size based on the sample size needed for a pre- and post-intervention assessment. A total sample size of 81 participants pre- and 81 participants post-intervention was required if the sample size is calculated based on two proportions (proportion 1: 40%; proportion 2: 20%) with a significance of 0.05 and a power of 80%. We therefore aimed to include a sample of at least 81 persons of each target group (persons affected and family members).

### Eligibility criteria

All participants had to live in the three *woredas* (districts) the study was conducted in. Because data from this study are used as baseline assessment for a project that aims to develop a family-based intervention for prevention and self-management of disabilities in the Ethiopian context, all persons affected had to have visible impairments due to their condition. Family members of persons affected needed to live in the same household as persons affected. Persons <15 y of age were excluded.

### Sampling methods

Participants were selected using purposive sampling. Persons affected by podoconiosis and LF were recruited in Zigem. A list of persons affected living in Zigem was prepared by local health extension workers, listing a total of 160 persons affected by podoconiosis and LF. These persons affected were then visited in their home and asked to participate. When participants were not present at home, the next house on the list was visited. Due to a misunderstanding about the total sample size needed, not all participants on the list were revisited and included in the final sample. In Injibara and Addis Kidam, leaders of associations of persons affected by leprosy were approached to find suitable participants. Participants who were affected by leprosy were recruited at monthly association meetings and later visited in their homes. Data were collected on the same day the participants were invited to participate. One or two family members, depending on the research assistant who collected the data, were selected by the persons affected from among those living in the same house, based on the age, availability and willingness to participate.

### Data collection

Three questionnaires were used to collect data on family quality of life, perceived stigma and activity limitations. In

addition, demographic information (age, gender, district, condition, family size and occupation) was collected. Data were collected from September 2017 to January 2018.

The Beach Center Family Quality of Life (FQOL) scale was used to assess the family quality of life of persons affected and their family members. The tool was originally developed to assess the family quality of life of persons with disabilities.<sup>50</sup> The tool consists of 25 items and has five subscales (domains): family interaction, parenting, emotional well-being, physical/material well-being and disability-related support. A maximum score of 125 can be obtained, with higher scores denoting better family quality of life. Since the tool had not been validated in Amharic before, we translated the tool from English to Amharic and translated it back to English to check the accuracy of the translation. Subsequently the FQOL scale was pilot tested among 20 participants before use. Pilot testing entailed administering the questionnaire to check whether the questions and answer options were understood and appropriate. Participants were also asked whether they thought the questions were clear and appropriate. Minor revisions to the translation were made based on the pilot test.

The SARI Stigma Scale was used to collect information about stigma experiences of persons affected. The SARI Stigma Scale was originally developed in Indonesia to assess leprosy-related stigma.<sup>48</sup> However, given that the areas of life affected by health-related stigma are remarkably similar for people with (stigmatized) chronic health conditions, we believe the tool can be used for other NTDs also.<sup>19</sup> The tool can be used to assess experienced stigma, disclosure concerns, internalized stigma and anticipated stigma. The tool contains 21 questions and its score ranges from 0 to 63, with higher scores denoting higher levels of stigma. The original English version of the tool was translated to Amharic and back-translated to English using different translators. We pilot tested the SARI Stigma Scale among 15 participants before use, using the same procedure for pilot testing as described above.

The Screening of Activity Limitation and Safety Awareness (SALSA) scale was used to collect data on the activity (limitations) of persons affected. The SALSA scale consists of 20 items of daily activities related to three domains: mobility, self-care and work. A total score of 80 can be obtained, with higher scores denoting more activity limitations. The SALSA scale has been validated in Amharic among persons affected by leprosy.<sup>49</sup> In addition, the SALSA scale has been found to be a valid instrument to measure activity limitations in persons with a locomotor disability.<sup>40</sup> In order to compare results between conditions, we decided to use the SALSA scale for all three conditions instead of separate disease-specific scales. Since no separate information about the severity of impairments was collected from the persons affected, the SALSA score also served as a proxy for severity of disabilities ('disability' is an umbrella term for impairments, activity limitations and participation restrictions).

Four health extension workers participated in the data collection process and interviews. The interviews of persons affected by podoconiosis and LF and their family members were performed in participants' homes. Persons affected by leprosy were interviewed in the leprosy association venue, in a private space. Family members of persons affected by leprosy were interviewed in their homes.

## Data analysis

All collected data were entered in SPSS (IBM, Armonk, NY, USA) and analysed by two independent researchers. Due to a change in the coordinator during the study and miscommunication about the total sample size needed per scale, not all participants were administered all three scales. Family quality of life was the dependent variable, while sociodemographic variables, perceived stigma and activity limitations were independent variables.

To get a better understanding of the overall family quality of life, perceived stigma and activity limitations of our sample, we performed simple descriptive analysis of the data, such as calculating (sub)group mean scores and 95% confidence intervals (CIs), looking for the most notable differences in scores between subgroups. Participants were excluded from the analysis if they had only completed the SALSA and SARI scales. We performed simple descriptive analysis of the data and independent samples t-tests to compare FQOL scores between participant groups and between FQOL domains, to meet our first objective.

Not all participants were administered all three scales. For this reason, we conducted one analysis on a cohort for which data on the FQOL and SALSA scale were available and one analysis on a cohort for which data on the FQOL and SARI Stigma Scale were available, to meet our second objective. A Spearman correlation was used to evaluate whether there was an association between family quality of life, stigma experience and activity limitations.

To meet our third objective, we performed univariate regression to determine whether there was a relationship between the independent variables (age, gender, condition, family size, occupation, SARI score and SALSA score) and dependent variable (family quality of life). In addition, stepwise multivariate regression with backward elimination was done to examine which of these variables had an independent effect on family quality of life. We made a separate model for persons affected and for family members. All variables with a p-value <0.2 identified in univariate analysis were selected in the first multivariate model. Variables with p-values  $\geq 0.05$  were then eliminated one by one until all remaining variables in the model had a p-value <0.05. Bootstrapping was performed for the family quality of life regression model of persons affected since the FQOL score was not normally distributed.

## Ethical considerations

Ethical clearance was obtained from the ethical review committee of the Health Sciences College at Debre Markos University. In addition, both the zonal health department of the Awi zone and the district health offices granted permission to conduct the study. Study participants were only enrolled once they were fully aware of the purpose of the research and the methods of data collection. All study participants were informed about their right to stop at any time during the interview and of the confidentiality of data. After describing the objective of the study, verbal informed consent was obtained from adult study participants. In addition, verbal consent from legal caretakers of participants <18 y of age was obtained.

**Table 1.** Socio demographic characteristics of persons affected by leprosy, podoconiosis and lymphatic filariasis and their family members

	Leprosy (n=76)		Podoconiosis (n=101)		Lymphatic filariasis (n=35)		Total (n=212)	
	Person affected (n=48)	Family member (n=28)	Person affected (n=32)	Family member (n=69)	Person affected (n=15)	Family member (n=20)	Person affected (n=95)	Family member (n=117)
Age, mean (SD)	51.9 (15.6)	41.5 (20.4)	47.6 (13.3)	34.3 (15.1)	42.7 (21.6)	26.0 (10.9)	49.0 (16.1)	34.6 (16.6)
Gender, n (%)								
Male	34 (70.8)	12 (42.9)	10 (31.3)	24 (34.8)	6 (40.0)	12 (60.0)	50 (52.6)	48 (41.0)
Female	14 (29.2)	16 (57.1)	22 (68.8)	45 (65.2)	9 (60.0)	8 (40.0)	45 (47.4)	69 (59.0)
Occupation, n (%)								
Farmer	30 (62.5)	15 (53.6)	11 (34.4)	24 (34.8)	1 (6.7)	7 (35.0)	42 (44.2)	46 (39.3)
Daily labour or trade	4 (8.3)	0 (0.0)	4 (12.5)	16 (23.2)	2 (13.3)	2 (10.0)	10 (10.5)	18 (15.4)
Student	0 (0.0)	6 (21.4)	0 (0.0)	12 (17.4)	0 (0.0)	10 (50.0)	0 (0.0)	28 (23.9)
Other <sup>a</sup>	11 (22.9)	5 (17.9)	3 (9.4)	16 (23.2)	1 (6.7)	0 (0.0)	15 (15.8)	21 (17.9)
Missing data	3 (6.3)	2 (7.1)	14 (43.8)	1 (1.4)	11 (73.3)	1 (5.0)	28 (29.5)	4 (0.0)
Living area								
Addis Kidam	39 (81.3)	21 (75.0)	2 (6.3)	1 (1.4)	0 (0.0)	0 (0.0)	45 (47.4)	22 (18.8)
Injibara	7 (14.6)	6 (21.4)	2 (6.3)	0 (0.0)	0 (0.0)	0 (0.0)	9 (9.5)	6 (5.1)
Zigem	2 (4.2)	1 (3.6)	28 (87.5)	68 (98.6)	15 (100.0)	20 (100.0)	41 (43.2)	89 (76.1)
Family size, mean (SD)	5.3 (2.3)	4.9 (1.9)	4.7 (2.1)	4.9 (2.3)	5.3 (3.3)	5.9 (2.5)	5.1 (2.3)	5.1 (2.3)
Scale administered, n (%)								
FQoL scale <sup>b</sup>	48 (100.0)	28 (100.0)	32 (100.0)	69 (100.0)	15 (100.0)	20 (100.0)	95 (100.0)	117 (100.0)
SARI stigma scale <sup>c</sup>	47 (97.9)	-	18 (56.3)	-	4 (26.7)	-	69 (72.6)	-
SALSA scale <sup>d</sup>	34 (70.8)	-	14 (43.8)	-	11 (73.3)	-	59 (62.1)	-

<sup>a</sup>Occupation 'other' includes beggars, weavers, housewives and persons who said they did not have a job.

<sup>b</sup>The Beach Center Family Quality of Life (FQoL) scale. This scale was administered to all participants (persons affected and their family members).

<sup>c</sup>The SARI stigma scale. This scale was administered to persons affected only.

<sup>d</sup>The Screening of Activity Limitation and Safety Awareness (SALSA) scale. This scale was administered to persons affected only.

## Results

### Demographic information

Our initial sample included 239 participants (122 persons affected and 117 family members). Of these participants, 95 persons affected and 117 family members of persons affected were administered the FQoL scale. Not all participants were administered all three scales. A total of 69 persons affected were administered the FQoL and SARI scales and 59 persons affected were administered the FQoL and SALSA scales. An overview can be found in Table 1). Twenty-seven participants were excluded from the analysis because they had completed only the SALSA and SARI scales.

### Stigma and activity limitations

The mean stigma score of persons affected by leprosy, podoconiosis and LF (n=69) on the SARI Stigma Scale was 22.3 (95% CI 19.7 to 24.9). With a score of 26.8 (95% CI 22.2 to 31.5), persons affected by LF and podoconiosis had significantly higher mean scores than persons affected by leprosy, who had a mean score of 20.2 (p=0.016, independent samples t-test).

The overall mean SALSA score of persons affected (n=59) was 37.6 (95% CI 34.0 to 41.2). With a mean SALSA score of 44.3 (95% CI 39.0 to 49.5), persons affected by leprosy (n=34) had significantly higher SALSA scores (more activity limitations) than the other participants (p<0.001, independent samples t-test).

Participants indicated that they experienced most activity limitations with regard to walking (walking bare foot, walking on uneven ground and walking long distances). More than 78% of the participants indicated they had difficulty walking. In addition, >18% of the participants indicated that they had problems with dexterity, for example, handling small objects, cutting nails, opening a bottle or jar or picking up things from the floor. Most participants <55 y of age faced no or only moderate limitations, while most of the participants who experienced severe and extreme activity limitations were ≥55 y of age (n=12/15). More detailed background information about stigma and activity limitations can be found in the supplementary material.

### Family quality of life of persons affected and their family members

The overall mean family quality of life score of persons affected and their family members was 71.7 (n=212). Persons affected

had significantly higher mean scores, indicating higher family quality of life, than family members on all domains (Table 2). When comparing mean scores between the three different conditions we found that persons affected by leprosy had significantly higher mean scores on the domains 'family interaction' ( $p < 0.05$ ) and 'parenting' ( $p < 0.001$ ), while persons affected by LF had significantly higher mean scores on the domain 'physical' ( $p < 0.05$ , independent samples t-test). The differences in overall mean family quality of life scores between the three conditions were not significant ( $p > 0.05$ , independent samples t-test).

Both family members and persons affected indicated that they were most satisfied that their family teaches children how to get along with others, show they love and care for each other and talk openly with each other. Family members indicated that they were dissatisfied with their family's access to transportation, the outside help that is available to take care of the special needs of family members and their family's way of taking care of expenses. Persons affected indicated that they were dissatisfied with their family's (lack of) friends or others who provide support, the outside help that is available to take care of the special needs of family members and their family's way of taking care of expenses. Persons affected and their family members had the highest scores on the family interaction domain, followed by parenting, disability-related support, physical/material well-being and emotional well-being.

### Relationship between family quality of life and stigma and activity limitations

There was no association between the FQOL and SARI scores ( $\rho = 0.088$ ,  $p = 0.47$ ; Spearman correlation). In addition, there was no association between the FQOL and the SALSA score ( $\rho = -0.13$ ,  $p = 0.925$ ; Spearman correlation).

### Factors influencing family quality of life

We created two different multivariate regression models for family quality of life, one for only persons affected and one for family members. Table 3 provides an overview.

The model for persons affected showed that women had a significantly lower mean family quality of life. This model explained 7% of the variability of family quality of life for persons affected (Table 3). In addition, univariate regression showed that persons affected who were farmers had significantly higher family quality of life scores ( $p \leq 0.05$ , independent samples t-test).

The model for family members showed that participants with a smaller family size and family members who worked in daily labour, trade or 'other' occupations had significantly lower mean family quality of life. This model explained 21% of the variability of family quality of life for family members (Table 4). Univariate regression showed that family members of persons affected by podocniosis had significantly lower family quality of life scores ( $p \leq 0.05$ , independent samples t-test), while family members of persons affected by LF had significantly higher family quality of life scores ( $p \leq 0.05$ , independent samples t-test). Female family members also had lower family quality of life, but this was not significant ( $p > 0.05$ , independent samples t-test).

## Discussion

### Family quality of life of persons affected and their family members

The present study found that persons affected by leprosy, podocniosis and LF had significantly higher levels of family quality of life than family members on all domains of the FQOL scale. This finding is supported by several qualitative studies that showed family members' support of their affected family member has a positive impact on the quality of life of persons affected but tends to adversely affect their own quality of life.<sup>41-43</sup> While the family is an important resource for the persons affected, the support needs impact the whole family.<sup>34,44</sup> In a case study,<sup>41</sup> this pattern is reflected where a son with disabilities rated his own quality of life high and his mother rated hers much lower, which is likely due to the same phenomenon.<sup>41,45</sup>

We found that persons affected and their family members were most satisfied that their family teaches children how to get along with others, show they love and care for each other and talk openly with each other. Persons affected and their family members were most dissatisfied with their family's resources (access to transportation and the family's way to take care of expenses) and support outside the family. This was also found in an earlier qualitative exploration of family quality of life by the same authors.<sup>34</sup> The quality of life dimensions participants were most satisfied with (family interaction, parenting and disability-related support) and least satisfied with (physical/material well-being and emotional well-being) were the same for persons affected and family members. This indicates that most can be gained on the physical/material well-being and emotional well-being domains.

### Stigma

Findings from this study show that persons affected by leprosy, podocniosis and LF experienced stigma. This finding is supported by studies conducted in different areas that also found high levels of stigma among persons affected by leprosy, podocniosis and LF.<sup>19,26-29,34,46,47</sup> With a mean score of 20.2, persons affected by leprosy in the present study experienced a similar level of stigma as in a study conducted in Indonesia.<sup>48</sup> The latter found a mean SARI Stigma Score of 15.4-21.6 in different areas.<sup>48</sup> A factor that likely contributed to the high levels of stigma in the present study are visible impairments (data now shown), which is supported by other studies.<sup>17,49,50</sup>

We found that persons affected by LF and podocniosis experienced significantly more stigma than persons affected by leprosy. We believe two things contributed to this finding. First, in the present study the persons affected by leprosy were all members of a leprosy association, in contrast to the persons affected by podocniosis and LF. Being an association member can contribute to moral and physical support in various ways.<sup>27,51-54</sup> Peer support can provide social, emotional and instrumental support. Helping others can also increase confidence in one's capabilities, improve self-esteem and self-efficacy and provide a sense of empowerment, which can make people more resilient to stigma and discrimination.<sup>55</sup> In addition, in this study the persons affected by leprosy had access to loans from their

**Table 2.** Mean scores on the Beach Centre Family Quality of Life (FQoL) Scale per participant group.

	Persons affected by leprosy (n=48)		Persons affected by lymphatic filariasis (n=15)		Persons affected by podoconiosis (n=32)		All persons affected (n=95)		Family members (n=117)		All participants (n=212)		p-value, persons affected vs family members <sup>a</sup>
	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	Mean	95% CI	
FQoL total score (range 25-125)	79.1	75.2-83.0	77.5	70.7-84.2	73.3	68.6-78.0	76.9	74.2-79.6	67.4	65.1-69.7	71.7	69.8-73.5	0.000
Family interaction (range 6-30)	22.7	21.7-23.8	20.7	18.4-23.0	20.8	19.4-22.3	21.8	21.0-22.6	19.1	18.3-19.9	20.3	19.7-20.9	0.000
Parenting (range 6-30)	22.8	21.7-23.9	19.7	17.3-22.1	19.5	17.9-21.1	21.2	20.3-22.1	19.2	18.3-20.1	20.1	19.4-20.7	0.002
Emotional (range 4-20)	8.7	8.1-9.4	9.3	8.1-10.6	8.9	8.2-9.7	8.9	8.5-9.3	7.3	6.8-7.7	8.0	7.7-8.3	0.000
Physical (range 5-25)	12.6	11.1-14.0	15.1	13.3-16.9	11.9	10.7-13.2	12.8	11.9-13.6	10.8	10.2-11.4	11.7	11.2-12.2	0.000
Disability support (range 4-20)	12.3	11.1-13.5	12.7	11.6-13.9	12.1	11.5-13.3	12.3	11.6-13.0	11.1	10.5-11.7	11.6	11.2-12.1	0.009

<sup>a</sup>Calculated using an independent samples t-test. P-value of the mean difference of the FQoL score between persons affected and family members.

**Table 3.** Correlations between family quality of life of persons affected and the other variables in the dataset. These model explained 7% of the variability of family quality of life of persons affected ( $r$ -squared = 0.068). Independent variables included in the model are age, gender, condition, family size, occupation, SARI score and SALSAs score.

	Regression coefficient	Standard error	p-value	95.0% CI	
Constant	86.991	4.081	0.001	78.872	94.387
Gender (female)	-6.851	2.581	0.009	-11.666	-1.652

**Table 4.** Correlations between family quality of life of family members and the other variables in the dataset. The model explained 21% of the variability of family quality of life of family members ( $r$ -squared=0.209). Independent variables included in the model are age, gender, condition, family size and occupation.

	Regression coefficient	Standard error	p-value	95.0% CI	
Constant	63.799	2.981	0.000	57.883	69.716
Family size	1.124	0.493	0.025	0.146	2.102
Occupation daily labour or trade	-8.412	2.987	0.006	-14.340	-2.484
Occupation 'other' <sup>a</sup>	-10.610	2.833	0.000	-16.231	-4.989

<sup>a</sup>Occupation 'other' includes beggars, weavers, housewives and participants who indicated that they do not have a job.

association. This is supported by Wang et al.,<sup>56</sup> who found that family income is associated with family quality of life. Second, the majority of the participants affected by podoconiosis and LF who were administered the SARI scale in this study were female. Some studies have found that women are more stigmatized than men.<sup>17,27,57</sup>

### Activity limitations

In the present study, persons affected by leprosy experienced significantly more activity limitations on the SALSAs scale than the other participants. This can be explained by the fact that persons affected by leprosy may experience foot, hand and eye impairments,<sup>12,17</sup> while persons affected by podoconiosis and LF mainly experience problems related to the lower limb or swelling of other organs like the scrotum.<sup>4,5</sup> On the SALSAs scale, 15 of 20 questions relate to dexterity and grip strength. Since LF and podocooniosis do not cause hand impairments, these questions are not directly relevant to persons with these conditions. The SALSAs scale was developed to assess activity limitations among persons with peripheral neuropathy, such as in leprosy and diabetes.<sup>58</sup> However, the scale was also found to be a valid instrument to measure activity limitations in persons with a locomotor disability.<sup>40</sup> Because of this, the SALSAs scale is more sensitive to limitations caused by leprosy. Therefore we did not compare SALSAs scores between participants. Future studies would benefit from using another tool to assess activity limitations among persons affected by LF and podoconiosis, such as the World Health Organization Disability Assessment Schedule 2.0 or the Green Pastures Activity Scale.<sup>59-61</sup>

### Relationship between family quality of life and perceived stigma and activity limitations

We found no association between family quality of life and stigma or between family quality of life and activity limitations. This is surprising, given the negative impact of stigma on mental well-being<sup>19,62</sup> and the impact of impairment on stigma.<sup>17</sup> We expect, given the key role of social support in mental well-being,<sup>63,64</sup> that social support can provide a buffer against stigma and discrimination.

### Factors that influence family quality of life

The findings of the present study showed that persons affected who were farmers reported a significantly higher family quality of life than other participants (e.g. persons working in daily labour or trade, students and 'others'). This is similar to findings from a study conducted in the Zhejiang Province in China,<sup>65</sup> showing that farmers reported higher health-related quality of life than other workers. A possible explanation is that farmers have more possibilities of self-direction and working.

In the present study, women affected reported significantly lower family quality of life. It could be that on top of the impact of their condition on their daily life, which is often higher for women,<sup>66,67</sup> women experience more caregiver stress, as women are often expected to be the family caregivers.<sup>44</sup> In Ethiopia, women are expected to be at home, caring for the family, and not taking on major social roles in education and employment.<sup>44</sup>

We also found that family members from families with a smaller size had significantly lower family quality of life. For some

families, the presence of an affected person in the family can be an additional socio-economic burden.<sup>68</sup> People with severe impairments are often unable to (fully) work and contribute to family income and incur health-related costs, which can be difficult for families with fewer resources. This impact is felt more directly in smaller families, where only a few people contribute to family income. In larger families, members in the household share the 'burden' of caring and supporting a family member with a disability.<sup>69</sup>

### Study limitations

Limitations of the study include the cross-sectional design, a relatively small sample size per participant group and the use of two tools not formally validated in Ethiopia (the FQOL and SALSA scale). However, we have translated both tools using forward and back translation and have extensively pilot tested the tools. The SALSA scale is not the optimal instrument to assess limitations due to podoconiosis and LF; it did, however, provide insights into activity limitations due to leg impairments. In a future study we hope to validate the scales and will be careful to administer all scales to all participants to compare between scores on the different scales.

### Conclusions

We found that persons affected had significantly higher family quality of life than family members. The family quality of life dimensions that were affected were the same for persons affected and family members, with the physical/material well-being and emotional well-being domains being affected most.

The persons affected by leprosy, podoconiosis and LF included in this study experienced stigma and the persons affected by podoconiosis and LF experienced significantly more stigma. In addition, the persons affected experienced activity limitations, mostly related to walking. We found no association between family quality of life and stigma or between family quality of life and activity limitations.

Women and families with a smaller size reported lower family quality of life. This indicates that efforts to improve family quality of life should give priority to women and families with a smaller size. Family quality of life is an important area to address because NTDs often affect the whole family. It is therefore important to provide appropriate support for persons affected and their family members.

### Supplementary data

Supplementary data are available at [Transactions](#) online.

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**Authors' contributions:** MW, AvtN and AS conceived the study. AvtN and AS designed the study protocol. MW supervised the fieldwork and collected the data. MW and AvtN analysed the data. AvtN drafted the manuscript. MW, AvtN and AS critically revised the manuscript for intellectual content. All authors read and approved the final manuscript. AS is guarantor of the paper.

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**Data availability:** None.

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