

Knowledge, attitudes and practices of health professionals towards people living with lymphoedema caused by lymphatic filariasis, podoconiosis and leprosy in northern Ethiopia

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Background: Podoconiosis, lymphatic filariasis and leprosy are highly stigmatised neglected tropical diseases that cause lymphoedema. Their enormous impacts on health-related quality of life, mental health and economic productivity can be significantly reduced by morbidity management and disability prevention (MMDP) services, but to deliver such services requires appropriate training of healthcare professionals. The aim of this study was to assess the knowledge, attitudes and practices (KAP) of rural Ethiopian healthcare professionals towards people with lymphoedema as a way to assess training needs.

Methods: This study used questionnaires to quantitatively assess KAP towards people with lymphoedema among rural healthcare professionals in northwest Ethiopia before and 12 months after a short training intervention.

Results: Questionnaires were administered to 14 health professionals at baseline and 21 at follow-up. At baseline, 71% (10/14) were found to hold at least one stigmatising attitude towards lymphoedema patients, compared with 66% (14/21) at follow-up. Large gaps in knowledge were noted, with many unable to identify ways of treating/preventing the diseases.

Conclusions: This study showed high proportions of healthcare workers holding stigmatising views and lacking essential knowledge about lymphoedema. To maximise the impact of MMDP interventions, further research is urgently needed to understand how to address these issues.

Keywords: attitudes, elephantiasis, health knowledge, leprosy, neglected diseases, practices, social stigma.

Introduction

Podoconiosis, lymphatic filariasis (LF) and leprosy are highly stigmatised neglected tropical diseases (NTDs) that cause lymphoedema and associated lower limb disorders.¹ Causing pain, disability and social isolation, these conditions significantly impair health-related quality of life, mental health and economic activity in the people they affect.^{2–6}

In an attempt to mitigate the impacts of podoconiosis, LF and leprosy, a number of morbidity management and disability prevention (MMDP) services have been successfully developed in

Ethiopia and other low-income countries.^{7–11} These services focus on encouraging simple self-care measures, including daily cleaning of affected limbs, application of ointments and bandages, leg exercises and elevation and wearing clean socks and shoes.^{12,13}

Ethiopia has a high burden of lymphoedema, with an estimated 1.53 million cases of podoconiosis, 5.6 million at risk of LF and 300 000 with leprosy.^{14,15} As such, the importance of MMDP services for lymphoedema has recently been recognised by the Ministry of Health¹⁴ and a large implementation study is currently under way with the aim of integrating routine MMDP services into

the Ethiopian health system, including not only physical self-care, but also mental health and psychosocial interventions for the three diseases.¹⁶

Support for such programmes from healthcare professionals will be fundamental to their success. Studies demonstrating the effectiveness of MMDP programmes have largely relied on trained volunteers or study staff to support patients with self-care,⁷⁻¹⁰ but for sustainability, these roles will need to be filled by local healthcare professionals. To positively impact quality of life in patients with lymphoedema, healthcare professionals will need training to ensure services are accessible, that clear and accurate information is given and that appropriate treatment is provided.

An important prerequisite for MMDP will thus be understanding the baseline knowledge, attitudes and practices (KAP) of local healthcare professionals towards people with lymphoedema. To date, several studies have investigated the KAP of healthcare professionals in similar settings towards podoconiosis.¹⁷⁻¹⁹ Alarmingly, one such study in Ethiopia demonstrated that all healthcare professionals surveyed held at least one stigmatising attitude towards people with podoconiosis,¹⁷ and in Rwanda, 76% of healthcare professionals were concerned that treating podoconiosis patients might risk their own health.¹⁹ Compared with podoconiosis, literature on LF and leprosy with respect to KAP towards MMDP services in Africa is lacking. There is also a dearth of research on how training interventions may impact on KAP. This study aimed to characterise KAP towards patients with lymphoedema among healthcare professionals in Ethiopia and review a simple training intervention.

Methods

Study setting

The study was conducted in the Gugsu Shikudad district in the Awi zone of the Amhara region of northwest Ethiopia. This setting was chosen due to the high co-endemicity for podoconiosis, LF and leprosy. Morbidity mapping of podoconiosis and LF cases in Awi from 2018 estimated a combined prevalence of 1.0% (1038 per 100 000 total population).³ The setting was also selected due to accessibility and a lack of conflicting MMDP programmes in the region.

Study design

The study used questionnaires to quantitatively assess KAP before and after a short training intervention (discussed in more detail below). Questionnaires were administered to a cohort of healthcare professionals at baseline and follow-up (12 months after the training intervention). There was some overlap between the cohorts at baseline and follow-up, but unfortunately questionnaire responses from the follow-up cohort could not be linked to the baseline cohort, thus the two cohorts were treated as independent in statistical analyses.

Study population

Healthcare professionals working at two sites within the Gugsu Shikudad district (Gusha Health Centre and Gugsu Shikudad Health Department) were invited to participate in the study. No

sample size calculation was done, as the aim was to capture as many healthcare workers as possible from the study sites. Moreover, all healthcare professionals working at the study sites who provided informed consent were enrolled non-randomly.

All cadres of healthcare professionals working at the study sites were eligible for inclusion, including nurses, health officers, midwives, pharmacists and laboratory technicians. The study team thought it was important to assess KAP relating to lymphoedema in all cadres of healthcare workers rather than just those who routinely manage patients with lymphoedema (in this setting, the majority of lymphoedema management is performed by nurses and health officers). This is because all cadres of healthcare workers may come into contact with patients at the health facility and thus have the potential to both positively impact outcomes for patients by making appropriate referrals to relevant team members and negatively impact patients via stigmatising attitudes. Where appropriate, results are aggregated by the cadre of health workers.

Study intervention: training of healthcare professionals

Between baseline and follow-up, all healthcare professionals received training in lymphoedema MMDP services, covering both physical and psychological management. Training was given in the form of a central 'training the trainers' 5-d course to some nurses and health officers in Bahir Dar town; this course consisted of lectures, practical exercises and discussions with patients. Those health professionals who attended the central 'training the trainers' course then went on to train the remaining healthcare professionals in a 1-d course. All healthcare professionals working at the study sites were able to attend training, regardless of whether they consented to enrol in the study.

Training was provided as part of the pilot phase (phase 2) of the Excellence in Disability Prevention Integrated across NTDs (EnDPoINT) study. EnDPoINT is a large implementation study aimed at integrating into the Ethiopian healthcare system a holistic package of care (including provisions for physical health, mental health and psychosocial needs) for people living with lymphoedema caused by podoconiosis, LF and leprosy. Further details on the protocol for the EnDPoINT study can be found elsewhere.¹⁶

Data analysis

All analysis was performed in Stata IC version 13 (StataCorp, College Station, TX, USA).²⁰ Descriptive statistics were collated and reported from questionnaire responses. Scores were generated for groups of questionnaire responses relating to KAP. Knowledge scores were generated by summing all correct answers from the knowledge section (Supplementary Table 1). Attitude scores were generated by summing all answers suggesting stigmatising attitudes from the attitudes section (Supplementary Table 2). Practices scores were generated by combining a score relating to actual practices by nurses and health officers with a score relating to beliefs about practices by all participants. Median scores were compared between participants at baseline and follow-up, with the difference in medians with 95% confidence intervals (CIs) generated using the *cendif* Stata command.²¹ Of note, questionnaire responses from the follow-up cohort could not be linked to the baseline cohort,

Table 1. Sociodemographic characteristics of healthcare professionals

Characteristics	Overall (N=35)	Baseline (N=14)	Follow-up (=21)
Age (years), mean (SD)	26.4 (4.5)	25.1 (3.2)	27.3 (5.1)
Male, % (n)	66 (23)	65 (9)	67 (14)
Time working in facility (years), mean (SD)	7.2 (5.5)	8.6 (5.4)	6.4 (5.5)
Education (years), mean (SD)	13.9 (1.4)	13.9 (1.4)	13.9 (1.4)
Current technical qualification, % (n)			
Health officer	23 (8)	21 (3)	24 (5)
Nurse	49 (17)	43 (6)	52 (11)
Midwife	9 (3)	14 (2)	5 (1)
Pharmacy	9 (3)	7 (1)	10 (2)
Laboratory	9 (3)	7 (1)	10 (2)

SD: standard deviation.

thus, while there was some overlap in participants, the two cohorts were treated as independent in statistical analyses. Moreover, as recruitment of participants was non-random, comparisons between baseline and follow-up data should be viewed with this limitation in mind.

Results

Sociodemographic characteristics of health professionals

Questionnaire data were collected from 14 health professionals at baseline and 21 health professionals at follow-up (Table 1).

The mean age of participants was 26.4 y and the majority were male (66%). The mean time spent in education was 13.9 y and the mean time spent working at the current health facility was 7.2 y. Participants had a range of professional qualifications, which reflected their daily job roles. Nurses comprised the majority of participants (49%), followed by health officers (23%), midwives (9%), pharmacists (9%) and laboratory technicians (9%).

Knowledge of lymphoedema caused by podoconiosis, LF or leprosy

The majority of participants had heard of lymphoedema caused by podoconiosis, LF or leprosy (100% [14/14] at baseline vs 95% [20/21] at follow-up) and had seen someone with one of these conditions (93% [13/14] at baseline vs 95% 20/21 at follow-up) (Table 2).

Contact with soil was correctly identified as a cause for lymphoedema (as is true for podoconiosis) by 64% (9/14) of participants at baseline and 100% (21/21) at follow-up. Two participants (14%) at baseline and six (29%) at follow-up identified mosquitoes as another correct cause (as is true for LF), while contact with affected people (as is true for leprosy) was identified by two participants (14%) at baseline and two participants (10%) at follow-up. Four participants (29%) at baseline erroneously thought lymphoedema could be caused by flies. No participants at either timepoint thought that lymphoedema resulted from a spiritual cause or stepping on dead animals.

The majority of participants believed that lymphoedema was treatable: 71% (10/14) of participants at baseline and 100% (21/21) at follow-up. Ways of treating lymphoedema that were correctly identified at follow-up included using soap (95% [20/21]), washing feet (90% [19/21]), using ointment (90% [19/21]), using socks and shoes (86% [18/21]), using bandages (86% [18/21]), elevating feet at night (81% [17/21]) and doing foot/leg exercises (81% [17/21]).

All participants were aware at both time points that lymphoedema is preventable. Wearing shoes was correctly identified by all participants at both baseline and follow-up as a means of preventing lymphoedema. At follow-up, washing feet after contact with soil was identified as a preventive measure by 86% (18/21) and cementing floors by 14% (3/21). No participants thought lymphoedema could be prevented by avoiding marrying people with the condition and their families.

Attitudes towards people with lymphoedema caused by podoconiosis, LF or leprosy

Attitudes towards lymphoedema caused by podoconiosis, LF or leprosy were assessed by asking patients if they agreed with a series of statements (Table 3). The majority of participants at both baseline and follow-up (baseline 71% [10/14], follow-up 95% [20/21]) felt that people with lymphoedema should have the same rights as anyone else. In contrast, however, 57% (8/14) at baseline and 57% (12/21) at follow-up believed that people with lymphoedema should be prevented from having children and 29% (4/14) at baseline and 33% (7/21) at follow-up believed that people with lymphoedema should not be allowed to make decisions, even those concerning routine events. 64% (9/14) at baseline and 86% (18/21) at follow-up stated they would eat food with someone with lymphoedema without complaint.

Practices in treating people with lymphoedema caused by podoconiosis, LF or leprosy

Practices in treating patients with lymphoedema were assessed in those health professionals who would routinely be expected

Table 2. Knowledge of lymphoedema in healthcare professionals

Knowledge	Overall (N=35), % (n)	Baseline (N=14), % (n)	Follow-up (N=21), % (n)
Heard of lymphoedema	97 (34)	100 (14)	95 (20)
Seen anyone with lymphoedema	94 (33)	93 (13)	95 (20)
Factors identified as causing lymphoedema			
Contact with affected people	11 (4)	14 (2)	10 (2)
Contact with soil	86 (30)	64 (9)	100 (21)
Flies	14 (5)	29 (4)	5 (1)
Mosquitos	23 (8)	14 (2)	29 (6)
Stepping on snakes or dead animals	0 (0)	0 (0)	0 (0)
Spiritual	0 (0)	0 (0)	0 (0)
Randomly occurring	3 (1)	7 (1)	0 (0)
Belief that lymphoedema is treatable	89 (31)	71 (10)	100 (21)
Ways identified for treating lymphoedema			
Washing feet	89 (31)	86 (12)	90 (19)
Using soap	89 (31)	79 (11)	95 (20)
Using ointment	71 (25)	43 (6)	90 (19)
Using bandages	60 (21)	21 (3)	86 (18)
Using socks and shoes	80 (28)	71 (10)	86 (18)
Doing foot/leg exercises	66 (23)	43 (6)	81 (17)
Elevating the feet at night	69 (24)	50 (7)	81 (17)
Belief lymphoedema is preventable	100 (35)	100 (14)	100 (21)
Ways identified as preventing lymphoedema			
Avoiding contact with cases	3 (1)	7 (1)	0 (0)
Avoiding marriage with cases and their family	0 (0)	0 (0)	0 (0)
Wearing shoes	100 (35)	100 (14)	100 (21)
Washing feet after contact with soil	86 (30)	86 (12)	86 (18)
Cementing floor of house	23 (8)	36 (5)	14 (3)

Table 3. Attitudes of healthcare professionals towards people with lymphoedema

Statement	Agreement with statement		
	Overall (N=35), % (n)	Baseline (N=14), % (n)	Follow-up (N=21), % (n)
People with lymphoedema should be prevented from having children	57 (20)	57 (8)	57 (12)
People with lymphoedema should not be allowed to make decisions, even those concerning routine events	31 (11)	29 (4)	33 (7)
People with lymphoedema should have the same rights as anyone else	86 (30)	71 (10)	95 (20)
If I am served together with someone with lymphoedema, I will eat the food with no complaint	77 (27)	64 (9)	86 (18)

to be involved in the direct clinical management of these patients, i.e. nurses and health officers (Table 4). At baseline, 33% (3/9) of nurses and health officers had experience treating patients with lymphoedema, compared with 56% (9/16) at follow-up. The proportion of nurses and health officers who had treated ≥ 10 patients was 11% (1/9) at baseline and 50% (8/16) at follow-up.

Lack of skills was the most common reason for not treating patients with lymphoedema, cited by 55% (5/9) of nurses and health officers at baseline and 63% (10/16) at follow-up. Lack of essential materials and supplies was given as another reason for 78% (7/9) of nurses and health officers at baseline and 19% (3/16) at follow-up. Fear of contracting disease was mentioned by 44% (4/9) at baseline and 6% (1/16) at follow-up. At the

Table 4. Practices among healthcare professionals towards people with lymphoedema

Practices	Overall, % (n/N)	Baseline, % (n/N)	Follow-up, % (n/N)
Actual practices (in nurses and health officers only)			
Experience treating lymphoedema patients	48 (12/25)	33 (3/9)	56 (9/16)
Number of lymphoedema patients treated			
0	52 (13/25)	67 (6/9)	44 (7/16)
0–9	12 (3/25)	22 (2/9)	6 (1/16)
≥10	36 (9/25)	11 (1/9)	50 (8/16)
Reasons for not treating lymphoedema patients			
Lack of skills	60 (15/25)	55 (5/9)	63 (10/16)
Lack of essential materials and supplies	40 (10/25)	78 (7/9)	19 (3/16)
Fear of contracting disease	20 (5/25)	44 (4/9)	6 (1/16)
Confidence in ability to treat lymphoedema patients	72 (18/25)	44 (4/9)	88 (14/16)
Beliefs related to practices (in all healthcare professionals)			
Belief in receipt of adequate education and training to perform job well	74 (26/35)	64 (9/14)	81 (17/21)
Belief in access to necessary materials and supplies to deliver good service	40 (14/35)	29 (4/14)	48 (10/21)
Belief that health facility provides everything needed to care for lymphoedema patients	71 (25/35)	50 (7/14)	86 (18/21)
Belief that lack of resources hinders delivery of quality care to lymphoedema patients	83 (29/35)	86 (12/14)	81 (17/21)

Table 5. KAP scores at baseline and follow-up

Score	Baseline (median)	Follow-up (median)	Generalized Hodges–Lehmann difference in medians (95% CI)	p-Value (Wilcoxon sum rank)
Knowledge	10	14	3 (1 to 5)	0.008
Attitudes	1	1	0 (–1 to 0)	0.389
Practices	2.1	3.2	0.9 (0.1 to 1.8)	0.042

outset, 44% (4/9) of nurses and health officers felt confident in their ability to treat lymphoedema, compared with 88% (14/16) at follow-up.

Beliefs about practices were assessed in all health professionals. The majority of participants felt they had adequate education and training to perform their jobs well (64% [9/14] at baseline, 81% [17/21] at follow-up). However, many believed both at baseline and follow-up that a lack of resources hinders delivery of quality care to lymphoedema patients (86% [12/14] at baseline, 81% [17/21] at follow-up).

Comparison of KAP at baseline and follow-up

An overall score was generated for each broad area of the questionnaire: knowledge, attitudes and practices (Table 5). These scores were then compared between baseline and follow-up with the aim of assessing the impact of the EnDPoINT training intervention on healthcare workers' KAP. These results should be viewed with caution given the limitations in the study design discussed.

The knowledge score was generated by adding all correct participant responses from questions relating to knowledge of lymphoedema caused by podoconiosis, LF or leprosy (Supplementary Table 1). As such, a higher knowledge score represented improved knowledge. Median knowledge scores were 10 and 14 at baseline and follow-up, respectively. The difference in medians was estimated to be +3 (95% CI 1 to 5), suggesting a significant improvement in knowledge scores between baseline and follow-up ($p=0.008$).

The attitude score aimed to assess the overall level of stigma in participants, with higher attitude scores reflecting higher levels of stigma (Supplementary Table 2). There was no significant difference in attitude scores between baseline and follow-up (median attitude score: baseline=1 vs follow-up=1; difference in medians 0 [95% CI –1 to 0]; $p=0.389$).

The practices score combined two elements, actual practices reported by nurses and health officers involved in the direct management of patients with lymphoedema and beliefs about practices reported by all study participants (Supplementary Table 3). A higher practices score was designed to reflect improved practices.

The median practices score was 3.2 at follow-up, a significant improvement from 2.1 at baseline (difference in medians +0.9 [95% CI 0.1 to 1.8]; $p=0.042$).

Discussion

This study highlights that a large number of healthcare professionals harbour stigmatising attitudes towards people with podoconiosis, LF and leprosy in Ethiopia. These results are consistent with previous studies in similar settings that found both high levels of community stigma towards people with lymphoedema^{1,6} and high levels of healthcare professional stigma towards people with podoconiosis.¹⁷⁻¹⁹

Thus the findings are concerning. High levels of stigma among healthcare professionals are likely to produce significant barriers to accessing care for patients.²² Indeed, fear of stigmatisation was cited as a reason to avoid attending healthcare facilities by several participants with LF in a recent qualitative study in Zambia.²³ Consequently, for patients with lymphoedema, stigma can cause reduced access to diagnosis and treatment and reduced adherence to medications.²² Stigma and misconceptions may also cause healthcare professionals to manage patients poorly or not at all,^{22,24} with this study showing a substantial proportion of healthcare professionals not treating patients due to fear of contracting disease.

Increasing health education is commonly proposed as a means to reduce stigma.²⁵ However, while results from this study are consistent with a training intervention being associated with a modest improvement in knowledge and practices, this did not translate to an improvement in the attitudes of healthcare professionals towards people with lymphoedema. The lack of impact on likely deep-set attitudes may be due to the relatively short duration of follow-up of 12 months, with previous studies over a similar timeframe showing no changes in stigma towards patients with podoconiosis.^{10,26} Lack of impact may also be due to the lack of focus in addressing stigma in healthcare workers within the training intervention, which mainly focused on increasing knowledge to promote self-care practices among patients. Furthermore, it may be that the apparent finding of a lack of impact of the training intervention on stigma was a consequence of the limitations of the study design, which are discussed in detail below.

Another notable finding from this study was the significant gaps in knowledge of the methods to prevent and treat lymphoedema among healthcare professionals, despite the high prevalence of the condition. Similar knowledge gaps have previously been demonstrated with respect to podoconiosis in another Ethiopian study.¹⁷ In this study, knowledge was apparently improved after a short training intervention, but a lack of essential skills was still cited as the most common reason to not treat patients.

This study has several limitations. The small non-random sample size makes any analysis beyond simple descriptive statistics hard to interpret, particularly regarding assessing the impact of the training intervention. Analysis is also restricted by the lack of pairing of datasets between baseline and follow-up, despite some overlap in participants. Further, due to the quantitative nature of the study, it is hard to fully understand the nature and root

causes of the stigma felt toward lymphoedema patients. In spite of these limitations, it is clear that this study highlights problematic KAP among healthcare professionals.

Conclusions

This study indicates that a large proportion of healthcare professionals in this rural Ethiopian setting hold stigmatising views towards patients with podoconiosis, LF and leprosy and lack essential knowledge about these diseases. As local healthcare workers will be key to delivering sustainable MMDP interventions, the findings warrant further exploration to ensure healthcare professional's KAP will not be a barrier to the successful delivery of services. Certainly the stigmatising attitudes reported herein could impede access to healthcare for people with lymphoedema and the knowledge gaps could impair the delivery of health education and support for self-care. Additional quantitative research using larger, more statistically robust studies will be important in determining the representativeness of this study and to assess the impact of training interventions. Qualitative research is needed to better characterise the views of healthcare professionals.

To overcome the potential barriers to MMDP services identified in this study, improved training and/or in-service supportive supervision of health professionals is clearly required. Resource limitations, another common reason given by healthcare professionals for not treating patients, will also need to be addressed. A further challenging but critical area for future study will be exploring how to target likely deep-set stigma within healthcare professionals. This will require, at a minimum, carefully developed social and behaviour change interventions based on formative local research.

Supplementary data

Supplementary data are available at International Health online (<http://inthealth.oxfordjournals.org>).

Authors' contributions: AF, GD, MS, OA and AT designed the study. OA, MK, AT and AF were involved in study implementation. RD and SB analysed and interpreted the data. RD initially drafted the manuscript, with OA, GD and MS contributing to the writing. All authors read and approved the final version.

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Data availability: Data are available upon request from the authors.

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