



**Ministry of Health
The Republic of Uganda**

Vector Control Division

**Knowledge, Attitude and Practices of Lymphatic
Filariasis Chronic Manifestation in Uganda**

December 2017

Executive summary

This knowledge, attitudes and practices (KAP) study is aimed at assessing the KAP relating to lymphatic filariasis (LF) morbidity and morbidity management in order to plan for large-scale intervention, including the regions within the study, with a focus on morbidity management and disability prevention (MMDP). The specific objectives for the survey were to obtain baseline data on KAP regarding LF morbidity and its management; to establish current efforts in the districts/region in addressing morbidity and morbidity management; and to assess anticipated intervention acceptance and identify potential barriers to acceptance of the planned intervention.

The study used mixed methods, including a quantitative household survey (1,981 households), qualitative key informant interviews (KIIs), and focus group discussions (FGDs) with sufferers of chronic LF conditions. Qualitative data was analysed through thematic and content methods, while descriptive statistics were used in the analysis of quantitative data.

The study established that the vast majority of participants had heard of LF and that there were strongly-identified local terms for lymphatic filariasis. Of the chronic conditions, people were more likely to associate lymphedema and elephantiasis with LF than they were for hydrocele. Mosquitos and mosquito bites were the most commonly cited cause and transmission route, and few people related LF to parasites or worms. The majority (93.5%) of respondents had seen at least one of the three LF manifestations, while about half (55.5%) saw people with these manifestations in their community. LF manifestations were more visible in Lira (65.8 %) and Yumbe (73.5%) than in Kitgum (24.5%). Very few respondents were found to have 'adequate' knowledge of LF and this was lowest in Yumbe, where only 2.3% had accurate knowledge on cause and transmission and were able to name at least two manifestations.

Within households, 16 LF cases were identified as a mix between hydrocele and lymphedema. Treatment for both was most commonly sought at health centres and there were low levels of satisfaction with the effectiveness of the treatment provided.

FGDs and interviews with LF patients or cases revealed high levels of pain, and inability to economically contribute to their households. Examples and instances of stigmatisation and isolation were common and it was noted that support of friends and families often dwindled with time. Health seeking behaviour was frequently pluralistic but almost always included at least one attempt at medical intervention. Many accounts of these interactions with health services were depicted as frustrating experiences which involved a lot of painful travel to get there; misdiagnosis; being told there was nothing that could be done; referrals which required more travel; doctors who were not there as arranged; or services that were too expensive to be taken up. Transport cost and inability to travel due to pain were extremely commonly-cited barriers to accessing services. Awareness of simple care routines for lymphedema was low and most respondents were under the impression that there was absolutely nothing they could do to improve their condition, outside of pain relief and using local herbs. For hydrocele,

surgery was usually known about and cited as the preferred option but availability and cost were too large barriers for them to take it up.

KIIs with service providers highlighted that planning was impeded by a lack of knowledge on the number of cases and their location. Resultantly, primary health care focused mainly on referrals to larger, more distant centres – a solution that the health providers themselves thought was inadequate and impractical for patients.

The report concludes with recommendations for:

- a tailored messaging campaign utilising the information in this study to maximise its effectiveness in reaching people and combatting stigma.
- localisation of service provision wherever possible, and utilisation of existing, more localised platforms – training VHTs is essential.
- an awareness campaign for simple self-care routines for lymphedema focusing on the quality of life aspects that taking up such a routine could bring to people.
- informing district planning teams on case management burden.

Foreword

Data collection for this knowledge, attitudes and practices study of lymphatic filariasis chronic manifestation in Uganda survey was carried out from 20 May to 18 June 2017 by the Ministry of Health Vector Control Division (VCD), covering the three districts of Lira, Kitgum and Yumbe. The survey was implemented with financial support from UK aid through Sightsavers.

The main purpose of the study was to assess the KAP of the population on lymphatic filariasis (LF) morbidity and morbidity management in order to plan for large-scale intervention, including (within the study's three regions), focusing on morbidity management/disability prevention. The study collected data on socio-demographic profiles of households, knowledge of causes and mode of transmission, attitudes towards prevention and morbidity management, and prevention and morbidity management practices.

Special thanks go to the study team whose core members were Mr Gabriel Matwale (Principal Investigator), Mr Richard Ocaya Kica (Research Coordinator), Mr Patrick Buyinza, Dr Edridah Muheki and Chris Iga (Co-Investigators). Others who provided support in different capacities include Mr Moses Okipi, Ms Laker Pamella, Ms Anna Auma and Mr Michael Tabuzibwa. Our thanks also go to the data collection teams and all survey respondents for their willingness to participate.

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Abbreviations and acronyms

ALB	Albendazole
FGD	Focus group discussion
HH	Household
INGO	International non-governmental organisation
IRS	Indoor residual spraying
IVM	Ivermectin
KAP	Knowledge, attitude and practice
KII	Key informant interview
LF	Lymphatic filariasis
MDA	Mass drug administration
NTD	Neglected tropical disease
PELF	Programme for Elimination of Lymphatic Filariasis
UGX	Ugandan Shillings
VCD	Vector Control Division
VHT	Village health team
WHO	World Health Organization

Introduction

Lymphatic filariasis (LF) is a filarial infection caused by thread-like parasites classified as nematodes (roundworms) of the family, Filariodidea. *Wuchereria bancrofti* is the only type of LF found in Uganda and is transmitted by *Anopheles* mosquitoes. Most people infected with LF are asymptomatic, though the infection is still causing damage to the lymphatic system and kidneys, and altering the body's immune system.

Those who become symptomatic have signs and symptoms ranging from acute to chronic, which develop years after infection. Acute episodes are local inflammation involving skin, lymph nodes and lymphatic vessels. Acute attacks play an important role in the progression of lymphoedemaⁱ. Chronic manifestations are lymphoedema (tissue swelling) that can progress into elephantiasis (skin/tissue thickening of limbs) and hydrocele (scrotal swelling). LF-related morbidities are now viewed as a great public health problem within endemic countriesⁱⁱ due in significant part to the related social stigma and financial hardship for the affected person and his/her household.

In Uganda, LF (with its accompanying chronic manifestation) has been documented in areas in the North, East, Busoga region (south of Lake Kyoga) and a small focus in Western Ugandaⁱⁱⁱ ^{iv}. It is estimated that more than 14 million people are at risk of acquiring the infection. The Programme to Eliminate Lymphatic Filariasis (PELF) in Uganda has two strategies: interrupting transmission of the disease through mass drug administration (MDA), promoting rational use of mosquito/bed nets and indoor residual spraying (IRS); and secondly, reducing suffering attributable to lymphoedema, elephantiasis and hydrocele through morbidity management/disability prevention. Since the inception of the programme in Uganda in 2002, considerable progress has been made in the interruption of transmission, with 100 per cent geographical coverage by 2010. Management of morbidity and disability prevention, however, have not been effectively addressed, so these are the main focus of the second phase of this programme.

The overall objective of this study was to assess the KAP of LF morbidity and morbidity management/disability prevention in order to plan a well-informed, large-scale intervention with a focus on morbidity management/disability prevention. The specific objectives were:

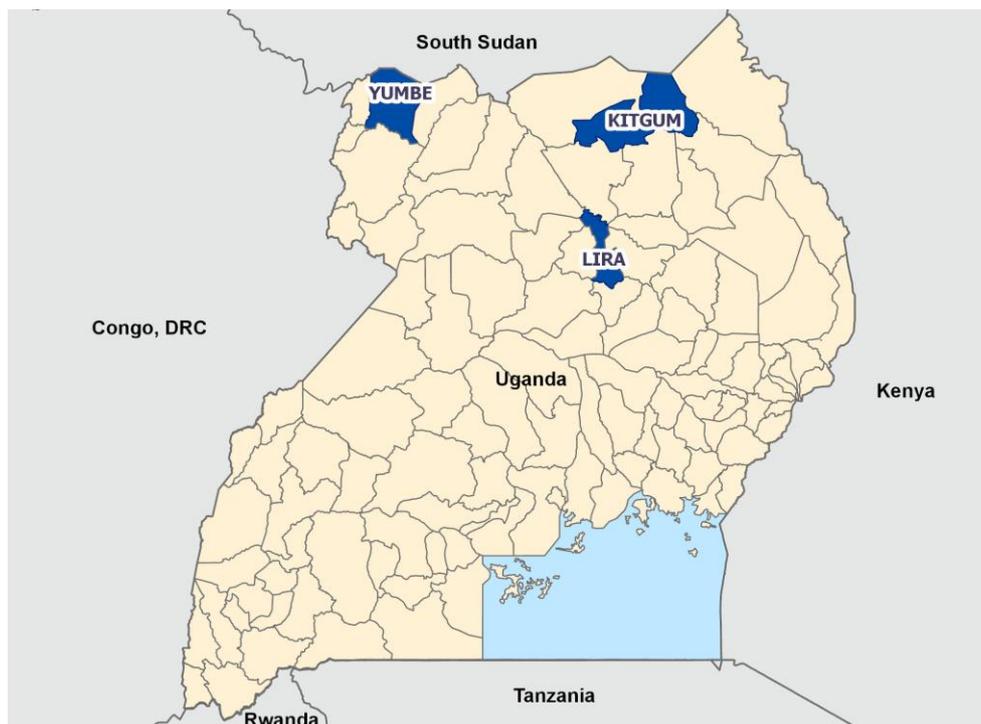
- i. obtaining baseline data on knowledge, attitudes and practices regarding LF morbidity and its management in the three sampled districts of Lira, Kitgum and Yumbe.
- ii. establishing current efforts in the districts/region in addressing morbidity and morbidity management/disability prevention.
- iii. assessing anticipated intervention acceptance and identifying potential barriers to acceptance of the planned intervention.

Methods

The study was conducted in the Lira, Kitgum and Yumbe districts in the Northern region of Uganda in a known LF transmission focus. The districts were purposively selected to provide a wide spectrum of geographical, socio-cultural, epidemiological and contextual variance. Data was collected from 20 May to 18 June 2017.

The study used mixed methods, including a quantitative household survey, qualitative key informant interviews (KIIs), and focus group discussions (FGDs) with sufferers of chronic LF conditions.

Map of the study districts



Household surveys

Households were selected using two-stage cluster sampling. In each district, 30 villages were selected, probability-proportionate to size using data from the 2014 national housing census. Within each village, 21 households were selected from existing household lists using a random number table. Within households, a single adult respondent (usually the household head or spouse) was selected and – with written informed consent – completed a household enumeration of all members and answered questions on lymphatic filariasis KAP. For the purpose of the study, a household was defined as comprising members who usually live in the unit, excluding visitors. Selected households were visited three times and if no respondent was available or did not consent, that household was replaced with another.

Quantitative data from the households was collected using online KoboCollect software and downloaded in MS Excel, then edited and exported to SPSS for analysis. Data was analysed un-weighted. The questionnaires were designed in English and translated to Luo and Aringa, then delivered in the most appropriate dialect.

Key informant interviews (KIIs)

Sixty-seven KIIs with various stakeholders (including health care providers, neglected tropical disease programme implementers, opinion leaders, and individuals living with LF)

were carried out. They were approached and informed consent was sought prior to conducting the interviews, which were recorded.

Focus group discussions (FGDs)

Six FGDs with individuals living with chronic manifestations of LF were conducted. People living with LF conditions were identified using sub-county held registers of those living with these chronic conditions. Those on the list were contacted and invited to participate, and their travel to the FGD location was facilitated. FGDs were facilitated using a semi-structured tool, groups were limited to no more than 12 people, and conducted in separate groups by gender. All FGD participants gave their informed consent, and FGDs were recorded.

Qualitative data from KIIs and FGDs that was audio recorded was transcribed (some in country and some by Anthrologica), translated into English (where the interview/FGD was conducted in local language), and then Anthrologica conducted thematic and descriptive analyses. Where respondents did not consent to the use of a voice recorder, the data was handwritten and checked for consistency.

Thematic analysis was performed on the transcripts of each KII and FGD, and descriptive analytics were conducted using Dedoose software.

Ethical approvals for the study were granted by the Research Ethics Committee at Vector Control Division (VCD) of the Ministry of Health, and the Uganda National Council for Science and Technology.

Results

Survey findings

Characteristics of households

The number of households surveyed was 1,981, with a total population of 9,878 persons enumerated and an average household size of 4.99. The majority (84.3%) of households earned their living from subsistence/peasant farming and more than a third (38.8%) of households spent, on average, less than UGX 4,000 per day, which falls below the poverty line of \$1.25 (UGX 4,500). Three quarters of the households had a male head and their average age was 44.19 (range 2-105) years. Adult literacy¹ was 69.6% and 71% had attended some form of primary education. Overall, a higher percentage of the respondents from Yumbe made their living from smallholder/subsistence farming and those from Yumbe were also more likely to have a household expenditure below 1,000 shillings a day (Table 1).

Characteristics of respondents

From each household, a single primary respondent was identified who provided information on all household members. The mean age of the primary respondents was 41 years (range 13-105 years) and 52% of the respondents were female. About a quarter (24.8%) of the respondents had never attended school. Of those who had attended, most (69.6%) had only attained some level of primary education. The adult literacy rate among respondents was 62.6%. Around 66.1% of respondents were household heads, while 28.4% were their spouses (Table 2).

¹ Defined as being 18 years and older and reporting being able to both read and write in a single language

Table 1: Socio-economic characteristics of households

Variable	Category	District			Total n=1,981
		Kitgum n=661	Lira n=666	Yumbe n=654	
Average household size		5.35	5.02	4.59	4.99
Average age of household head (years)		46.67	44.13	41.52	44.19
Percentage of male household head		76.4%	79.2%	68.3%	74.8%
Adult literacy rate		70.5%	75.5%	61.8%	69.6%
Education level of household head	Never attended school	17.9%	17.6%	13.5%	15.0%
	Lower primary (P1-P4)	14.1%	13.5%	17.6%	14.1%
	Upper primary (P5-P7)	37.4%	38.4%	31.4%	35.8%
	Lower secondary (S1-S4)	20.5%	22.7%	15.6%	19.7%
	Upper secondary (S5-S6)	3.4%	2.6%	1.2%	2.6%
	Post-secondary	6.7%	10.0%	3.4%	6.8%
Major source of income	Peasantry	87.1%	73.9%	92.0%	84.3%
	Casual labour	23.1%	21.2%	9.9%	18.1%
	Brewing alcohol	5.4%	3.8%	2.9%	4.0%
	Business	25.6%	25.2%	9.3%	20.1%
	Salary/wage	11.2%	15.2%	4.0%	10.1%
Daily household expenditure	0-1,000/=	2.7%	4.7%	11.5%	6.3%
	1,000-1,999/=	9.1%	6.9%	7.6%	7.9%
	2,000-2,999/=	14.7%	8.0%	12.7%	11.8%
	3,000-3,999/=	16.0%	11.7%	10.6%	12.8%
	4,000- 4,999/=	12.4%	12.2%	8.9%	11.2%
	5,000/= and above	45.1%	56.6%	48.8%	50.2%

Table 2: Socio-demographic characteristics of the respondents

Variable	Category	District			Total n=1,942
		Kitgum n=672	Lira n=666	Yumbe n=603	
Relationship to head of household	Is HH head	66.1%	62.8%	69.8%	66.1%
	HH head's spouse	26.7%	32.4%	25.7%	28.2%
	HH head's child	5.6%	3.0%	2.5%	3.8%
	Other relationships	1.5%	1.8%	2.0%	1.8%
Age	Mean (years)	42.92	41.39	39.78	41.42
	0-17 years	2.2%	0.6%	1.5%	1.4%
	18-24 years	11.0%	11.4%	15.6%	12.6%
	25-59 years	66.0%	72.7%	68.5%	69.1%
	≥60 years	20.8%	15.3%	14.4%	16.9%
Sex	Male	48.0%	46.7%	47.4%	47.4%
	Female	52.0%	53.3%	52.6%	52.6%
Education	Never attended school	20.5%	18.3%	36.8%	24.8%
	Lower primary (P1-P4)	14.7%	17.0%	18.9%	16.8%
	Upper primary (P5-P7)	39.2%	37.4%	28.9%	35.4%
	Lower secondary (S1-S4)	18.0%	17.7%	11.4%	15.9%
	Upper secondary (S5-S6)	2.7%	2.7%	0.5%	2.0%
	Post-secondary	4.6%	6.9%	0.5%	2.0%
Literacy rate	Can read and write in English or Kiswahili or Luo or Aringa	65.0%	69.2%	52.7%	62.6%
	Can read and write in English	37.2%	38.2%	27.6%	34.6%
	Can read and write in Kiswahili	0.8%	1.4%	5.2%	2.4%
	Can read and write in Luo	64.6%	67.5%	0.0%	45.6%
	Can read and write in Aringa	0.0%	0.0%	44.4%	13.8%

Knowledge of LF

The majority (81.8%) of respondents had heard of LF. When asked about the local name for LF, 98.1% of respondents in Kitgum and 93.5% of respondents in Lira named it Apim/Longo. In Yumbe, the majority (83.9%) of respondents called it Muringa/Ewapa. Of those who had heard of LF, 89.9% associated it with lymphoedema or elephantiasis, while 61.4% associated it with hydrocele. The majority (70.0%) of those who had heard of LF knew at least two of the three LF morbidities of interest. Knowledge of the symptoms of LF was higher in Kitgum district (85.2%) and Lira (82.6%) than in Yumbe (35.8%). Besides these three morbidities, other perceived symptoms of LF were itching, general body pain, numbness, dark skin and red eyes.

Table 3: Knowledge of the symptoms and causes of lymphatic filariasis (LF)

Category	n=# who've heard of LF	Kitgum	Lira	Yumbe	Total
		n=481	n=628	n=482	n=1,591
Symptoms of LF infection	Lymphoedema or elephantiasis	96.5%	95.2%	76.3%	89.9%
	Hydrocele	84.4%	78.7%	16.0%	61.4%
	Know at least two of the symptoms of LF	85.2%	82.6%	35.8%	70.0%
Cause of LF	Worms/parasites	21.0%	16.1%	21.6%	19.2%
	Mosquito bites	14.1%	25.3%	32.8%	24.2%
	Supernatural powers	17.9%	33.1%	3.3%	19.5%
	Antisocial behaviour	1.5%	0.8%	1.2%	1.1%
	Eating certain foods	1.0%	0.8%	0.8%	0.9%
	Drinking certain drinks	0.4%	0.5%	1.0%	0.6%
	Contact	1.2%	1.8%	3.1%	2.0%
	Don't know	50.5%	33.6%	41.5%	41.1%
	Others	8.5%	11.3%	8.5%	9.6%
Transmission of LF	Mosquito bites	13.5%	24.4%	33.0%	23.7%
	Worms/parasites	18.5%	14.3%	21.2%	17.7%
	Supernatural powers	15.6%	29.6%	3.5%	17.5%
	Contact	3.3%	3.7%	3.5%	3.5%
	Antisocial behaviour	1.5%	1.3%	1.2%	1.3%
	Eating certain foods	1.0%	1.0%	1.0%	1.0%
	Drinking certain drinks	0.4%	0.5%	0.6%	0.5%
	Don't know	50.7%	35.2%	40.5%	41.5%
	Others	9.1%	12.2%	8.7%	10.3%

When asked about the causes of LF, respondents commonly stated mosquito bites, followed by worms/parasites and supernatural powers. Of the 80.8% who did not identify worms/parasites as the causative agent, only 34.2% later agreed with the statement that "lymphoedema, elephantiasis and hydrocele can be caused by a parasite". Where respondents associated LF with supernatural powers, the majority (87.2%) perceived that its transmission will also be supernatural and that they were not at risk of infection (60.8%).

About a quarter (23.7%) of respondents correctly identified mosquito bites as the mode of transmission for LF. This was higher in Yumbe (33.0%) than in Kitgum (13.5%) and Lira (24.4%). Respondents who identified mosquitoes as the vector for LF also associated mosquitoes with the transmission of lymphoedema (83.3%), elephantiasis (76.5%) and hydrocele (51.3%). Misconceptions of LF transmission included witchcraft, stepping on traditional medicine, sharing shoes, dew, bad luck, genetics, drinking dirty water, sharing shower buckets, and high-risk sexual behaviour. Foods such as carrot and millet, and drinks such as mwenge bigere, malwa and waragi were also perceived to cause LF.

Table 4: Respondents' perceptions on the causes of LF manifestations

Cause of LF manifestation	Lymphoedema	Elephantiasis	Hydrocele
	n=661	n=666	n=651
Don't know	31.7%	23.7%	36.7%
Mosquito bites	18.2%	16.6%	11.1%
Witchcraft/spirits	15.9%	14.2%	4.1%
Worms/parasites	15.0%	12.5%	10.3%
Other	6.4%	5.0%	11.3%
Contact with infected person	1.8%	1.4%	1.2%
Antisocial behaviour	0.6%	0.4%	1.3%
Eating certain foods	0.5%	0.5%	0.4%
Drinking certain drinks	0.4%	0.5%	0.5%

When asked about the causes of the three LF morbidities, the majority (85.0%) of respondents lacked correct knowledge of the causes of lymphoedema, while 89.7% lacked accurate knowledge of the causes of hydrocele. About one in 10 respondents (15.9%) associated lymphoedema with witchcraft.

The majority (93.5%) of respondents had seen at least one of the three LF manifestations, while about half (55.5%) saw people with these manifestations in their community. LF manifestations were more visible in Lira (65.8 %) and Yumbe (73.5%) than in Kitgum (24.5%). The most visible manifestation was lymphoedema/elephantiasis (89.9%), followed by hydrocele (73.8%).

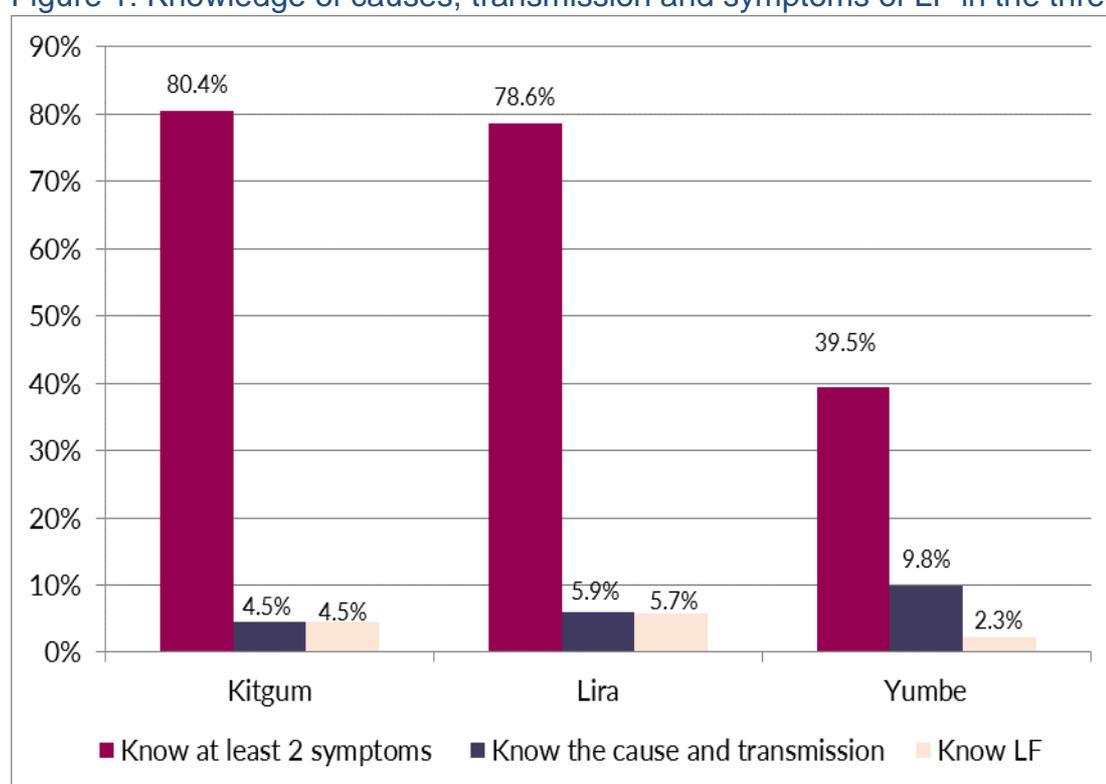
Table 5: Visibility of LF in communities

	Kitgum	Lira	Yumbe	Total
	n=3,536	n=3,342	n=2,993	n=9,871
Have seen/or know about persons with lymphoedema or elephantiasis	96.5%	94.3%	76.2%	89.9%
Have seen/or know about persons with hydrocele	80.3%	79.7%	59.7%	73.8%
Have seen/or know about persons with lymphoedema or elephantiasis or hydrocele	96.9%	95.4%	86.9%	93.5%

Have seen people with lymphoedema or elephantiasis in their community	6.0%	41.8%	62.0%	38.0%
Have seen people with hydrocele in their community	15.6%	45.8%	46.2%	34.9%
Have seen people with lymphoedema or elephantiasis or hydrocele in their community	24.5%	65.8%	73.5%	55.5%

In this study, adequate knowledge of LF was defined as accurate knowledge of the cause and transmission of LF and at least two manifestations of LF. 4.3% of the respondents were found to have adequate knowledge. This was higher in Lira (5.7%) than in Kitgum (4.5%) and Yumbe (2.3%). Figure 1 shows the trend in knowledge of the causes, transmission and symptoms of LF across the three districts.

Figure 1: Knowledge of causes, transmission and symptoms of LF in the three districts



Adequate knowledge of LF was associated with the level of education ($\chi^2=52.559$, $p<0.001$) and the locality/district where the respondent resides ($\chi^2=7.885$, $p<0.019$).

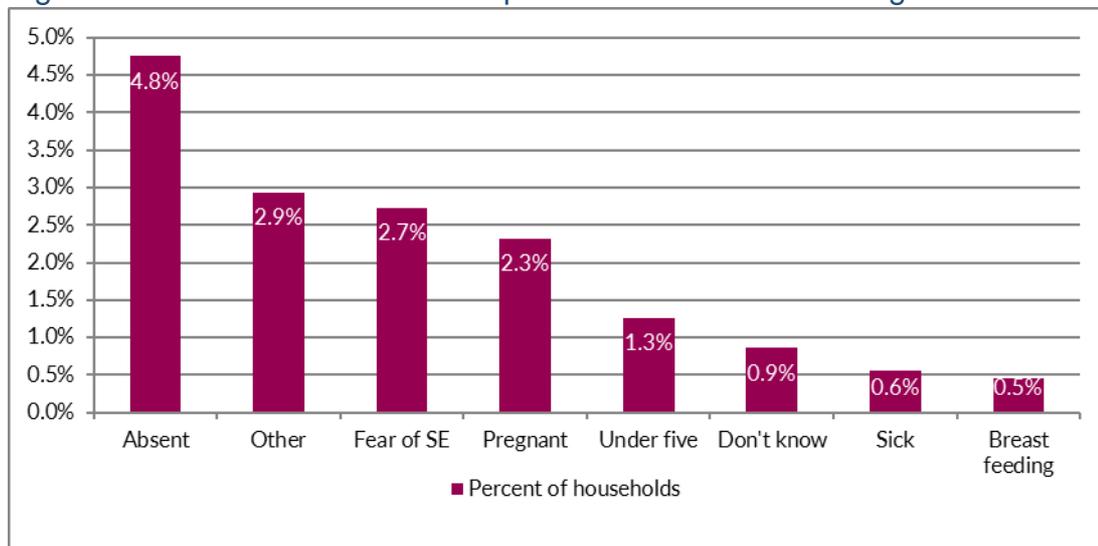
Table 6: Showing breakdown of adequate knowledge among respondents

Variable	Categories	Adequate knowledge			Significance
		Yes n=1643	No n=115	Total n=1758	
Sex	Male	57.7%	47.7%	48.1%	$\chi^2=2.994$ $p=0.084$
	Female	42.3%	52.3%	51.9%	
Age	0-17 yrs	1.3%	0.9%	0.9%	$\chi^2=1.126$ $p=0.771$
	18-24 yrs	9.0%	12.0%	11.9%	
	25-59 yrs	74.4%	69.6%	69.9%	
	≥60 yrs	15.4%	17.4%	17.3%	
Education level	Never attended school	7.7%	24.7%	23.9%	$\chi^2=52.559$ $p<0.001$
	Lower primary	14.1%	16.4%	16.3%	
	Upper primary	28.2%	36.6%	36.2%	
	Lower secondary	25.6%	15.7%	16.2%	
	Upper secondary	10.3%	1.8%	2.2%	
	Post-secondary	14.1%	4.8%	5.2%	
District/ locality	Kitgum	37.2%	35.8%	35.8%	$\chi^2=7.885$ $p<0.019$
	Lira	47.4%	35.4%	35.9%	
	Yumbe	15.4%	28.9%	28.3%	

Prevention and control via mass drug administration

The majority (92.0%) of households received Ivermectin (IVM) and Albendazole (ALB) treatment. Figure 2 shows the main reasons for non-uptake of IVM and ALB.

Figure 2: Reasons for non-consumption of IVM and ALB during MDA



Mass drug administration (MDA)

Of the 284 households that had LF cases, 93.4% had received MDA with IVM and ALB. It was noted that 85.1% of the households that did not receive IVM and ALB had village health teams (VHTs) in their village. Further analysis showed that the majority (85.3%) of these households were within a 5km radius of their nearest health facility. 42.3% of these households perceived that they were not at risk and 47.2% perceived that elephantiasis, scrotal swelling and lymphoedema were not common in their community so there was no need to worry about them.

When asked about the benefit of the treatment, respondents who participated in the MDA commonly reported that treatment expels intestinal worms (65.3%), prevents elephantiasis/hydrocele (40.1%) and prevents LF infection (33.4%). Other benefits of treatment were that it cleared body rashes, made fleas and lice disappear, reduced malaria, cut down medical expenses, cured stomach pain and improved eyesight.

Morbidity management

Household respondents were asked about any member of the household suffering from a chronic LF manifestation and a total of 16 LF cases were reported. The majority (13) of the LF cases were peasant farmers and two were schoolboys with no source of income. Moreover, nine of the cases were from households with a daily household expenditure of UGX 5,000 and above. Ten of the LF cases were within a 1-3km radius of their nearest health facility.

When asked about morbidity management techniques, three of the seven lymphoedema cases said they washed their limbs with soap. The first treatment options for lymphoedema cases were a health centre/hospital (2), VHTs (1) and traditional herbs (1). It was perceived that the treatment received from the health centres/hospitals did not alleviate the symptoms. In the event of an acute attack, most (5) of the lymphoedema cases sought treatment from a health centre/hospital. The remaining two per cent did not seek treatment during acute attacks.

Hydrocele manifested in two thirds (10) of the LF cases. The first treatment option for hydrocele cases were a health centre/hospital (6), VHTs (1) and traditional herbs (1). Of the six cases that sought treatment from a health centre/hospital, five perceived that the treatment

offered did not alleviate the symptoms, while one was unable to follow the advice given due to the cost.

Qualitative findings

Overview of key informants

Gender	Female	17
	Male	50
District	Kitgum	29
	Lira	15
	Yumbe	23
Position	Individual living with lymphatic filariasis	7
	Chief	7
	Opinion leader	2
	Community Development Officer	8
	District Health Educator	2
	Health Inspector	3
	District Health Officer	3
	Health Assistant	3
	In-charge, RN	9
	Local Council III Chairperson	8
	Medical Superintendent	2
	Midwife	1
	Public health nurse	2
	Registered Nurse	6
	Secretary of Health & Education	2

Overview of FGDs

Condition	Location	Gender
Hydrocele	Kitgum	Male
	Lira	Male
	Yumbe	Male
Lymphoedema	Kitgum	Female
	Lira	Female
Elephantiasis	Yumbe	Female

Perceptions and experiences of disease burden

Disease prevalence and lymphatic filariasis data

- It was noted by providers, community members and service users in each of the three districts that LF was no longer a common condition. However, there was some discrepancy in their perceptions of how rare it is. A public health nurse at Kochi Health Centre III in Yumbe District reported that they had only seen three cases of the condition in the previous three years, while one subcounty Chief stated,

“There are people who are having these cases though it is not at very high prevalence, but there are these cases at least in every village in our sub-county”.

- Participants who worked at health facilities, typically reported few cases

presenting at their facilities, while participants working in communities described cases as uncommon but still present. As a Community Development Officer in Kitgum concluded,

“Because I always work with farmers in this area and each and every time I move around the community I see these cases are there”.

- A number of respondents noted recent declines in the disease burden of lymphatic filariasis and attributed this to prevention activities, such as mass drug administration and community sensitization:

“The cases of the diseases were present in the past but currently the cases do not exist anymore due to the drugs which were being given to the victims in the sub-county” (Chief, Kitgum).

- Many participants reported that, to their knowledge, there was infrequent or no data being collected on incidence of LF in their catchment areas. A few respondents thought data may be being gathered through higher level health centres where laboratory diagnosis for the disease and surgeries for hydrocele take place. One participant also noted that diagnostic capacity in the area poses a logistical challenge to accurate data collection on incidence,

“The diagnosis of these diseases is also a challenge because not many laboratories in the district are there to diagnose the disease” (Medical Superintendent).

The low burden of the disease in the area was noted by many providers as a challenge for identifying and collecting data on incidence. As one respondent explained,

“Cases of Lymphatic Filariasis are very rare these days and even the health workers are not well versed with it” (In-charge, Kitgum).

- The health-seeking behaviours of people with LF was also noted by many respondents as shaping the ability to gather data on the burden of disease in each of the districts. For example, a health assistant reported,

“I do not personally know any person suffering from lymphoedema, elephantiasis, or hydrocele reporting to this facility since I joined here as a health worker, but I have been hearing that they are out there in the community”.

The Chief of the same sub county further emphasised,

“Scrotal swelling could be present among the people in the community but the locals have that tendency to fear exposing it to the people around them and rare cases of elephantiasis probably do exist in the community since the people who suffer from those morbidities tend to hide themselves”.

Rural versus urban burden

Most participants described a distinct difference in the disease burden between rural and urban areas, with all except one indicating that the disease is much more common in rural areas. This difference was linked to environmental, behavioural, and infrastructural risk factors.

- The difference in disease burden between rural and urban populations from environmental causes was frequently linked to differences in exposure to the vectors of the disease. Commonly mentioned were factors such as proximity to lymphatic filariasis vector (mosquito) breeding grounds,

“In rural areas people can easily acquire the disease due to the environment, rivers and swamps that can breed the known cause of elephantiasis” (In-charge, Kitgum).

- The lifestyle and behaviour that was highlighted as a contributor to increased exposure among rural populations, was due to

“General farming activities where persons go very early in the garden and come back late, exposing themselves to the effects of bites of black flies and mosquitoes” (Medical Superintendent, Kitgum).

- Participants also linked the perceived higher burden of the disease in rural areas to variations in health education rates between rural and urban populations. Rural areas were described as having less exposure to health education and higher rates of traditional health beliefs, shaping prevention, health seeking and management behaviours in ways that increase the disease burden.

“Rural populations don’t acquire good health education and they are not aware of the measures of prevention of Lymphatic Filariasis” (In-charge, Kitgum).

In contrast, urban areas were described as being,

“A bit civilised and sensitised hence they tend to seek medical attention” (In-charge, Kitgum).

- Even among the rural population who sought medical care, health care access and availability were noted as factors contributing to greater disease burden in these communities. As a nurse from Kitgum concluded,

“Better health facilities and easy access to roads in urban areas make the disease burden different in the urban and rural population”.

Similarly, a District Health Inspector explained,

“The housing aspect in the rural area exposes [those populations] to the disease as compared to the housing aspect in the urban population”.

Physical

- The most commonly-noted symptom for all of the conditions associated with the disease was intense pain. This pain was described as: **“Throwing a person down”**. Many narratives described how the pain would spread from a specific area to overtake the entire body. In contrast, a few providers and one participant with hydrocele suggested that hydrocele symptoms were not painful.
- Cold temperature was commonly noted as a factor contributing to increased pain, as well as condition flare-ups in general. As one participant with hydrocele explained,

“From this thing that I have caught [Lymphatic Filariasis], it grabs hold of my intestines and when it does this I cannot walk, I must stay down. Secondly, it makes the whole of your body be in pain and you feel very cold. It makes everything on your body be in pain including your head, everything on your body pains. That is what it causes on your body. It feels worse when it is raining and cold. When it is cold, you can't come out. It will require you to be in warm place; that is how it affects me”.

- Many respondents noted that the conditions associated with LF cause severe disability in those suffering from the disease. People with associated conditions were described as being unable to move, conduct household chores, participate in community events, travel, work, engage in sexual activities, or have children.
- Some respondents further described that people suffering from swelling of the limbs or scrotum suffered from problems related to clothing and shoes. As one participant stated,

“The disease affects some of the people who get marginalized, take the example of the elephantiasis, you can't put on shoes” (Chief, Yumbe).

Not only was apparel highlighted as a practical problem for people with these conditions, but there was some ambiguity on appropriate clothing and its availability. One provider noted that compression clothing, if available, would be recommended to help with swelling. Other respondents described the necessity of loose clothing to accommodate the swelling. Further, availability of appropriate clothing and footwear was seen to affect where people could go, the activities they could participate in, how they would be received and how they felt about their condition.

Economic

- The impact that the disease and associated conditions had on a person's productivity was noted by providers, community members and those with the disease across all districts. This was particularly true for those living in rural areas

where communities were dependent on agriculture and construction. Respondents described how difficulties in undertaking work were compounded by difficulties travelling to and from employment. Beyond making physical labour difficult, participant narratives highlighted that engaging in physical labour, particularly during cold seasons and cool times of the day, could exacerbate their condition(s). As one participant with lymphoedema/elephantiasis in Yumbe explained,

“It stayed for one week and disappeared, when I went back to start digging my leg immediately started swelling. My head became painful, I got a swelling on the other end of my leg. When these signs started, I started vomiting, when I start vomiting, I felt very cold I didn't eat, I only took a little water, I did not eat for one week, I just stayed like that. I went to buy drugs (panadol), I took it then I cooled down. I stayed then this thing started coming back slowly by slowly then it also started disappearing, when it started disappearing, I tried to go back to dig, when I started digging that thing started coming back from there it started coming on and off until it now swelled permanently”.

- In addition to having reduced earning potential, participants spoke about the additional costs that people suffering from LF incurred attempting to treat and manage their conditions.

“They cannot even work for money due to the problem of the disease but instead they would spend a lot to look for the ways to reduce on their pain” (In-charge, Kitgum). Additional expenses may be associated with treatment and medicines, transportation to health facilities, dressings, hygiene products and appropriate and warm apparel.

Social

- Respondents often described the impact that the disease had on the social lives of those with the condition, contributing to neglect, isolation and family breakdown. When asked about his social situation, one participant explained it to be:

“Very negative, even my own relatives are now tired of me because I am unable to contribute actively to the income in the house, they are tired of taking care of me” (Participant with hydrocele, Kitgum).

- Neglect of persons suffering these conditions was a pervasive theme among interviews with providers and community members,

“Sometimes they are also neglected by their own family and this always bring stress and pressure and this people tend not to survive for a long period of time” (Community Development Officer, Kitgum).

This theme of neglect was raised in the narratives of people suffering from the disease, many of whom expressed the desire to feel loved and cared for. One participant with hydrocele in Kitgum suggested that improved care would be a:

“Facilitating factor that would make me feel loved and still wanted by the government as well [as] the community”.

- Many participants described how LF sufferers were isolated from society. Beyond the physical limitations of their condition, which restricted their engagement in many community activities, the fear of contagion also contributed to their isolation.

“The patient feels isolated because the community thinks that it can easily be spread making it hard for this person to live freely” (Public Health Nurse).

A sub-county chief of Kitgum district stated,

“Their houses are built far away from the rest of other people due to fear of them spreading the diseases and as the result, they are neglected in the community” (Chief, Kitgum).

Some community members and opinion leaders described how those with the conditions were expected not to share things like chairs and plates, making it challenging for them to join communal events.

- The conditions associated with the disease were noted as being the potential cause of family breakdown. This was most commonly associated with a wife leaving a man with hydrocele because of his inability to produce and support a family and to perform sexually. One participant with hydrocele in Kitgum, Orum, emphasized:

“What should be noted here was that it led to my family divorce; as a result of the disease my wife left me, giving the reason that I can no longer produce a child”.

However, another participant with hydrocele in Lira claimed that hydrocele was more acceptable than other conditions, stating:

“Some women leave/divorce when they learn that you are suffering from elephantiasis, but for hydrocele they can sometime tolerate the condition”.

Various responses indicated that understandings regarding the disease and its cause play an important role in levels of social acceptability, although from the available data it was unclear how this impacted marital choices or if there were regional variations.

- Accounts of how the disease had a negative impact on the social aspects of a person’s life were pervasive and arose across all participant groups and all districts. The social impact narratives were more varied and nuanced among those research participants actually suffering from LF. While some respondents with the disease described experiences of neglect and isolation, it is important to note that others spoke of family and community support and acceptance. For example, one participant with lymphoedema/elephantiasis concluded,

“My husband does not give a negative response, he handles me well, in fact

when this thing started he is the one looking for medicine for me, he buys and brings the medicine for me. He does not complain at all. Even the other family members the same, they give me support”.

Stigma

- Stigma was commonly mentioned and appeared to shape health seeking behaviours, social interactions, and the mental health and wellbeing of those suffering from LF. Importantly, many participants described self-stigma among persons with the disease as contributing to their poor lived experiences and health outcomes. As one nurse in Lira, explained,

“They tend to fear the other community members because they look at themselves as abnormal thereby isolating themselves from other members of the community”.

- Health belief models about the causes of LF also contributed to the stigma associated with the condition. A nurse from in Lira District explained,

“The general belief that the community has is that this Lymphatic Filariasis, especially lymphedema or elephantiasis, is caused by witchcraft. This is responsible for a lot of disputes and wrangles in the community”.

Interestingly, associations with witchcraft were not always inherently negative. One participant with hydrocele in Kitgum, Akwang explained that it actually protected them against overt stigma,

“The community thinks that I am being bewitched because no test confirmed that it's hydrocele traditionally or medically, so they don't talk much at my back”.

Others believed causes included the will of God. In some cases, this is also described as protecting against stigma, while in others it appeared to be the basis of stigma. One community development officer in Kitgum explained,

“These are associated with profound beliefs and norms that the conditions are brought about by bad luck, unworthiness before God, a person of bad character, etc. Therefore, community members would not advise people to stay close to the individuals affected with these kind of diseases”.

- Participants described stigma associated with the physical symptoms of the conditions, such as people laughing at visibly-enlarged scrotums that could be seen through clothing, or the look and smell of the wounds. A participant with lymphoedema/elephantiasis noted,

“I suffer because other people are saying bad things about me and sometimes I feel uncomfortable when the fluid comes out of my leg when I am with my friends”.

Further, the clothing and shoes that a person suffering from one of these

conditions must wear to accommodate the physical effects of the disease may be the subject of ridicule. As described by a participant suffering from hydrocele:

“Before this sickness, I used to dress very smart, but now when I wear a belt, this thing starts and I start to feel pain. When other people see you, they start making a fool you and say ‘look at this one with his sickness’. So you find that in most cases when you are doing your thing people just laugh at you. But there are people who know and understand, they will say this is because of sickness”.

- Stigma was also frequently mentioned in association with the economic impact of the conditions, with people with LF frequently being described as a burden, and dependent on family members and well-wishers for their food and medication. One health worker in Kitgum, concluded,

“This condition increases the burden of responsibility of taking care of the affected persons since he/she needs to be taken to hospital and food stuff provided since he/she cannot produce on their own now”.

- Some participants with the disease, related stories of family members and community members who viewed them as lazy due to their inability to be productive. In discussing how he was perceived, one participant with hydrocele explained,

“If you do not go to the garden, she thinks that you are lazy, that it is not sickness even after seeing this thing, she still wants you to go to the garden, now if you do not go, that's when she will decide to leave you and go away”.

A few participants described how other people believed they were faking their symptoms in order to avoid contributing. One participant with hydrocele reflected,

“Because of the boy's condition, some family members, brothers, sisters, and parents, use abusive words and offensive language at times, for example when the boy is experiencing pain and other children are doing some household chores, they felt this boy is faking illness”.

Mental health

- The physical, economic and social impacts of the disease, coupled with experiences of stigmatisation, were frequently noted among participants as contributing to increased stress and mental health issues for those with the disease. A health assistant explained,

“Patients always have intense social stigma and maltreatment from the society which greatly stress the patient and at times leads to mental illness”.

Participants noted other contributors to stress, including living with the incredibly disabling symptoms, struggling with poverty, seeking health care and maintaining treatment.

- Depression, loss of dignity and low self-esteem were also frequently described in relation to having LF. A participant with hydrocele in Kitgum District explained,

“I have low self-esteem and despise myself, I feel worthless living. I cannot participate actively in any community functions”.

Participants with the condition often described uncertainty and lack of concrete hope, leaving them in a state of unhappiness; and these sentiments were also reflected by others. A community development officer in Yumbe, concluded,

“I think they are not happy because I talked to one and he said to me ‘I am not happy because I don't know when this sickness is going to leave me, I'm not certain of the date therefore I cannot be happy at all’. They will be happy when they know at a given time that the sickness will go away but since he was not certain he told me he is not happy”.

- Uncertain diagnoses, limited resources to pursue treatment and management, and lack of a cure for lymphoedema and elephantiasis all contributed to ‘lost hope of life’. Hopelessness was also described as shaping health seeking and management behaviours (see the section on Health seeking behaviours: explanations of illness).
- A few participants noted that pain, stress, depression and hopelessness became so severe that some of those suffering from the disease hoped for death. As a local council representative from Yumbe, described,

“Mentally they are tortured by their condition, so they can't live a normal social life and they are definitely deprived of their happiness, some of them even sometimes wish for death”.

- A number of participants with LF expressed ways in which their faith (Muslim, Christian) helped them cope with the stress and uncertainty of their condition. One participant with hydrocele explained,

“So I tell them this is the will of God so I will not fear or be ashamed because it's the will of God”.

and another described the way in which faith and social norms in the religion contributed to a good relationship with his community,

“Because they know this is sickness and it's not of human beings' making, it is God's making. They do not mistreat us, they relate well with us, they look for ways of how they can help us”.

While demographic data on participants' religions was not available, the protective influence of religion on mental health issues and stigma associated with lymphatic filariasis should be further researched.

Models of illness

The way in which people seek a diagnosis and manage and treat their illness is often shaped by how they understand the illness and its causes. Across the study districts, participants suggested a variety of models of illness that often had layered components of biomedical, traditional, and religious understandings. In addition to the biomedical causes of the disease, participants' narratives also highlighted causes – including an act of God, witchcraft, and curses – as punishment for social transgressions.

- Biomedical models of health and illness, specifically around neglected tropical diseases, are being promoted through programmatic efforts to sensitise communities in Uganda. These efforts were seen to influence health seeking behaviours in the communities included in the study. As one nurse in Yumbe, explained:

“First of all, in this community, the first thing that will ring in their minds is they are being bewitched. They can go to meet herbalists, but now with sensitisation, they will come to the nearby health centre then they can be referred”.

Participants noted, however, that sensitisation efforts have not reached all communities where traditional health belief models remain strong. People suffering from the disease in these communities were described as being more likely to seek out traditional forms of health care.

- Witchcraft as a cause for LF was frequently noted by providers as a community-level belief. A health assistant explained,

“The community in the catchment area of the health facility strongly believes that Lymphatic Filariasis is a result of witchcraft and charm, therefore before embarking on medicine [from health facility] they first make attempts to manage the condition using [traditional] herbs before coming to a health facility. This is the general procedure of how most lymphedema and elephantiasis patients start their morbidity management”.

Those seeking traditional treatments not only delayed getting the help that they needed from health centres, but also incurred costs for treatment that were unlikely to improve their condition, and risked doing more harm. As a public health nurse in Yumbe, explained,

“Since the community still have this local belief, those with the condition manage it traditionally by making cuts around the affected part to relieve them of the pain, but instead it causes more infection and swelling”.

A number of participants described sourcing their own herbal medicines. As one participant with lymphoedema/elephantiasis in Yumbe, Kochi, described,

“I just take herbs from trees without differentiating between the good and bad ones, because I don't know what to do”.

- Participants suggested that traditional forms of healing were often sought after biomedical care was unable to offer hope of a cure or good, sustainable management options. A number of providers noted the difficulty of getting patients to attend health centres for treatment,

“Even when you advise those with the disease to go for medical treatment, they don't take it seriously and do not go, the reason being the disease [elephantiasis] has no cure” (Provider, Yumbe).

- Health seeking behaviours for all of the conditions associated with the disease were impacted by lack of availability of curative therapies. As a local council representative in Yumbe, Lodonga concluded,

“Because they don't have definite source of drugs for curing, they decide to go local to the herbalist for treatment to reduce on the pain”.

The lack of a successful cure for the clinical symptoms of lymphedema and elephantiasis, combined with cost and travel barriers, made some participants perceive that seeking care for their condition at a health centre was a futile option. As one participant with hydrocele in Kitgum noted,

“No, I do not know of any initiatives apart from the hospital, where they failed to help me. I should even say I don't know completely because even the general hospital can't help and I don't feel like going back”.

This sentiment appeared to be stronger among sufferers of lymphoedema and elephantiasis than those with hydrocele, mainly because there is a surgical option for hydrocele that has the potential to cure the condition.

Outreach

- Participants frequently reported that health education outreach and sensitisation efforts had changed the way affected individuals understood the disease, and this altered their health seeking behaviours in a positive way. It also helped address knowledge gaps concerning prevention and available management and treatment options. Awareness of the symptoms that may indicate LF and knowing about options of where to go for help were recognised as highly important for increasing attendance at health centres. As a nurse from Lira District recommended,

“The facility can also be supported to organise outreaches to give health education talk and sensitisation about Lymphatic Filariasis to rid their minds of the belief and myths they have about the Lymphatic Filariasis, how it is spread and how it can be prevented or managed”.

- VHTs were noted as identifying and referring people in the communities with the

conditions indicative of LF and, in turn, referrals were noted by the majority of participants in connection with patient health seeking behaviour. It was unclear, however, if these referrals were responsible for increased attendance at health centres or if those who attended health centres were motivated by other factors. In discussing referrals, a nurse from Lira, stated,

“Some clients come when they have been referred by VHTs while others come on their own to understand the medical context of their condition”.

Fear

- Fear of stigma was a dominant theme that emerged across all districts in regards to health seeking behaviours, with those suffering from the disease being described as fearful of presenting to health centres, and fearful that people would know they had the condition. As a public health nurse from Yumbe, concluded:

“People with this condition tend to shy away and end up not showing up in health facility but remain at home in the communities, and they have their reasons as why they do that. For instance, they are stigmatised and they experience too much pain due to the swelling of the legs”.

A community development officer from the same area agreed,

“They fear they don't want somebody to know that they have it. They cover it up. If you know that person you can go to him in a way that he feels he can show up [to the health centre] and explain the problem. I think you can be able to help him. Also, other people fear the operation”.

- There was also fear associated with the option of surgery for hydrocele, and a few participants suggested that surgery could make a person sterile or impotent. During a focus group discussion in Lira, men with hydrocele agreed that:

“Most women are against the operation of hydrocele because they think that during the operation the sperm duct of their husbands might be cut, hence making them impotent”.

- Another commonly-cited factor leading to delayed health seeking behaviour was the magnitude of the condition. Health care providers and those suffering from the condition both discussed the fact that patients waited until the condition started to have a major impact on their life before seeking treatment at health centres. This links to issues of poverty and attitudes of hopelessness (as discussed above). Prioritising resources to seek health care is often a last resort. A patient with hydrocele in Kitgume, Akwang concluded:

“I just went for medical treatment when the pain escalated. This is how I manage the pain”.

- A number of participants with the disease also noted that the severity of the condition could preclude health seeking, when the level of pain and other symptoms became too debilitating for them to present at facilities (see also the

section on Barriers to health care access: physical limitations).

Feasibility and effectiveness

Recommended management of the long-term conditions associated with lymphatic filariasis includes maintaining good hygiene to prevent secondary infection; wearing appropriate apparel to avoid aggravating painful swelling; administration of pain killers and anti-inflammatory drugs to relieve pain; and antibiotics to treat infection.

- These management strategies could only be followed if supplies (soap, dressings and medication) were available and accessible for the patient. Limited and inconsistent availability and/or prohibitive costs associated with material resources made it unfeasible for some patients to adhere to the management strategies. A participant with hydrocele in Kitgum explained,

“It is going to kill me, let it do so, because I don't have the money needed for treating it”.

- A key recommendation for LF management is to rest and avoid physical labour when the conditions appear. Following this advice was challenging for many patients, particularly those with few economic resources and whose livelihood was dependent on physical labour, such as farming or construction work. As one participant with hydrocele stated,

“Because now if you do not work, how will you survive? So you just force yourself to work”.

Another participant with hydrocele explained,

“I went to Kumi Hospital. The doctors told me I should not dig with this thing and I should not cut big trees. I should not ride a bicycle. When I am going out in the cold I should not miss to put on footwear. If I go to dig I should put on a Gumboot. What I have not followed is because of poverty. I don't have a Gumboot. I just go to the garden barefoot”.

- Both perceived and experienced effectiveness of a treatment or management strategy emerged as factors that influence adherence. Participants often described different self-management strategies, including the use of medicines and local herbs, maintaining hygiene, wearing various apparel, conducting ceremonies, surgery, and cutting. In discussing their management strategies during focus groups, most participants agreed that painkillers given by the health centres helped with discomfort.
- Among the participants, the effectiveness of local herbs was more contested than biomedical approaches, with most providers describing local herbs as useless or even harmful. Participants who had used local herbs to manage their conditions had varied experiences. Some found that the local herbs did nothing to ease their pain, while others found them to be highly beneficial. One participant with

hydrocele explained,

“When it starts like this I think if I use ‘Kineji’ [local herbs], it could help... When it starts being painful we buy a razor blade, we start cut it then apply Kineji applied in it. it is painful but then it cools down”.

A participant with lymphoedema explained that although he appreciated painkillers from the health facility, they did not stop the fluid leaking from his leg wounds, so he used a local herb to reduce the pain and stop the fluid.

Reputation

- Participants broadly agreed that the reputation of a source of care, treatment or medicine influenced their uptake. For example, surgery was understood to be a positive intervention for hydrocele, and this encouraged other patients to seek and accept surgery. Many respondents – both patient and provider – described the surgery for hydrocele as a way to “cure” the disease. Others noted post-surgery relapse that further contributed to attitudes of hopelessness associated with the disease.

Cost

- LF is a disease that is most commonly found among the rural poor and, as discussed above, exacerbates inequities, contributes to economic stress by reducing earning potential while requiring higher expenditure (for instance, to seek health care and pay for medicines). Participants frequently identified these issues as major barriers to accessing health care. A participant with hydrocele explained,

“My mother took me to the hospital and they asked for 150,000 Ugandan Shillings [approximately GBP 32] but my mother did not have any money and we came back. Now I am looking for money. I don't know whether it [hydrocele] will burst. If it bursts, I will just die. So that is what stresses me. I can't afford the treatment yet”.

Another participant with hydrocele in Kitgum, Akwang, explained,

“I went for traditional herbs in Akwang sub-county because there is a man known for treating such conditions. I got the herbs but they still did not cure the condition. Then last year a medical team came to Akwang Health Center III so I went again and they said I needed surgical operation but at a cost of 400,000 Ugandan Shillings [approximately GBP 85]. The challenge is that I am a farmer, I can't afford such an amount”.

- Costs associated with treatment also impacted social relations. Some patient participants described trying to borrow money from other people to afford treatment, with promises to pay them back when they were well and able. One participant with hydrocele in Kitgum, Orom, explained,

“I made a promise to them that I would pay the money back when I got

better. But I failed to get the money”.

Participants struggled to borrow money, and while they did not elaborate on why people refused to lend them funds, it was likely linked to the pervasive attitude that the disease is incurable. This in turn contributed to stigma and the notion that people with LF are a burden on their families and communities. Indeed, one participant described his children taking the money intended for his pain medication and spending it on other items.

- Cost was also noted in relation to traditional and herbal medicines, and a number of providers suggested that people suffering from the disease wasted money on traditional remedies that could not help their condition.

Transportation

- Lack of appropriate transport was highlighted across all districts as a barrier to accessing health facilities which had the capacity to treat and manage conditions. Remote locations, challenging terrain and poor road conditions were also mentioned by some respondents as adding to the challenge of travel.
- In addition, several participants described how their physical condition made travelling to health facilities more challenging. Although walking was reported to be “incredibly painful” for many people with LF, most participants were forced to walk because they did not have the financial resources to use other modes of transport, even if they were available. Participants emphasised,

“It is not easy because of the pain to walk, or even sit on boda boda [motorbike taxi]”.

Another participant with lymphoedema/elephantiasis explained that although he had been to hospital twice previously,

“This time I am too weak to go to the hospital. I can’t be helped”.

Although frequent follow up is recommended by providers to manage conditions, regularly presenting at health facilities was understood to be increasingly challenging as the severity of conditions increased.

Administrative barriers

- Even when participants were able to present at health centres, many described additional barriers to accessing care, including having the appropriate paperwork. Patient narratives recounted inconsistencies in referral procedures and accompanying documentation, which caused confusion about the care system and treatment seeking. A patient with hydrocele in Kitgum explained,

“The pain I undergo made me decide for myself to go to the hospital, hoping that I will be treated and cured. To my surprise when I went to Kitgum general hospital and was referred verbally to St. Joseph hospital, I was blamed for not having written referrals for them to know where to start their investigation”.

- Long waiting times due to high numbers of patients at health centres was also highlighted as a barrier. A community development officer described instances

“Of not attending to victims of these diseases due to high numbers of patients in the health centre”.

Providers also suggested that LF was not necessarily prioritised for prompt treatment. This was echoed by a patient with hydrocele in Kitgum, Orom, who recalled that:

“Getting the service was not easy. It took very long hours of waiting because of the many patients with other conditions [who were seen before us]”.

- Several patient participants described overcoming barriers to present at a health centre, only to find the health staff were absent, in some cases even when appointments had been made. A participant with hydrocele recalled,

“I went to Midigo Hospital. This thing [Lymphatic Filariasis] threw me down. I was taken by my father, I was checked. The doctor said this thing has matured, I should come in again on Monday. When I came back on Monday I found the doctor had gone to Kampala, so the operation was not conducted. I was given some capsules. I started taking the capsules. When it reached the next Monday, when we went back, there was no proper information and we do not know about the whereabouts of the doctor up to now”.

- Participants (both patients and providers) frequently described drug shortages at health centres. A Secretary for Health and Education confirmed stock-outs were common,

“When we identify these people with these conditions and refer them to the health centres, there may be no drugs because sometimes there are no drugs in the health centres”.

and a Medical Superintendent asserted:

“There is also a challenge of storage of the drugs, in fact, the district has no storage facility”.

Health centre capacity

- A major barrier to the provision of care was the limited number of health centres, particularly those of a sufficiently high level to diagnose and treat LF and the associated conditions. Many providers noted that the health centre that they worked at was fairly new, suggesting that the number of facilities may be increasing, but the lack of referral centres remained a dominant issue among participants. A Secretary of Health and Education confirmed,

“For the case of health centers we have only one grade III center which is Makuma Health Center and the two are grade II which are not able to manage this condition. So these are the challenges. Some help to upgrade these Health Centers to grade III would be good”.

- Diagnostic capacity was highlighted as a barrier to care provision. One Medical Superintendent acknowledged that:

“Sometimes people present with the symptoms but we are not able to diagnose due to lack of knowledge and equipment to diagnose... The diagnosis of these diseases is a challenge because there not many laboratories in the district to diagnose the disease”.

- Similarly, providers agreed that in addition to drug stock-outs, there was limited health facility infrastructure in terms of theatre capacity, resulting in patients not always receiving the surgery they required (as discussed above from the patient perspective). A District Health Officer explained,

“In the district capacity to carry out these operations, currently we have only one theatre at the main hospital carrying out the surgery”.

- It was also noted that health centres had growing populations in their catchment areas and this could inversely affect both access to care and quality of care. A Medical Superintendent discussed the influx of refugees from neighbouring countries to their area, suggesting:

“One challenge is the population has gone up because of the refugees, so issues or shortages arise”.

Health care personnel

- Participants described ways in which health care provision at the district level was shaped by human resources for health and personnel availability. The level of a health facility dictates the cadre of health personnel staffed there, which in turn dictates the types of care that can be offered. In many cases, the front-line provider

at health facilities was a nurse with basic training. The technical capacity of health workers impacted their ability to provide adequate care for patients with LF. Although some health staff at lower level health facilities, some VHTs, and some outreach workers had received general training on neglected tropical diseases, it was felt by many participants that health staff would benefit from specific training on the identification and management of LF and the associated conditions.

- Absenteeism was also raised as an issue by participants, with many posts being unstaffed. As a District Health Educator explained,

“When it comes to the human resource in terms of the surgery, we have a very big problem because the medical officers are very few, sometimes they are overburdened with work”.

- Poor morale of health care workers was mentioned by numerous participants, and the negative influence this had on health care provision. As one District Health Inspector noted,

“There is understaffing and these few staff are not well motivated, which makes it very difficult for the programme to be rolled out”.

Morale among outreach workers was also raised, with participants suggesting that providing water, lunch or remuneration to outreach workers – for example, community drug distributors – would better facilitate their work and improve motivation.

Outreach capacity

- Limited transportation and the lack of fuel were dominant challenges raised in relation to outreach activities, including mass drug administration and sensitisation programmes. As a Community Development Officer explained,

“When it comes to the problem of transport in the sub-county, you find that we only have one motorcycle... It is only when I need it that I use it, but if the local council chairman has a programme, he uses it, and if the sub-county chief has a problem, he also uses it. Then it becomes a little bit difficult for us to carry out our activities”.

In discussing recommendations to improve service delivery, a local council chairperson agreed,

“The key request is transport facilities be given so that the staff can go to the villages to sensitize people with the aim of eliminating these conditions”.

- The lack of sustainable funding was highlighted by providers in terms of their ability to implement programmes and outreach. As one District Health Officer concluded,

“In terms of the district capacity to carry out these activities, we have gaps in funding. For instance to sensitise on radio, we need [mobile phone] airtime. Most programmes that come to the district with components of health education and health promotion are not usually given enough budget allocation, yet sensitisation is supposed to be a continuous activity because

behavioural change cannot be achieved in one day”.

Facilitators to health care access

Localised treatment delivery

- Given the numerous challenges with accessing health care, it is unsurprising that many participants highlighted the need for close-to-community service provision, and saw this a major facilitator for seeking and receiving care. In this respect, many participants mentioned the important role of VHTs in providing drugs and other services ‘on the doorstep’.
- ‘Surgical camps’ were also credited with bringing skilled teams into local areas to provide hydrocele surgery, and there was demand for increasing such services. Participants from some districts included in the study confirmed that surgical camps had taken place in their localities, while others requested their introduction. For example, one District Health Educator confirmed,

“One thing for Lymphatic Filariasis is in relation to the surgery. To me it would be important to organize a surgical camp for to cater for those people”.

Outreach and sensitisation

- The majority of participants described outreach and sensitisation efforts as being a facilitating factor in encouraging patients to present for health care. Participants described how outreach activities enabled VHTs to actively identify affected people at the community level, offer them immediate services and refer them to health centres. According to many participants, sensitisation efforts were key in raising awareness about health care availability and services, and in providing communities with health education about prevention, symptoms and management of the disease.

Disability services

- Government-supported disability services were not frequently discussed in interviews, but when raised, participants acknowledged the potential of such services; however, some questioned whether they were available for patients with LF and related conditions. The District Health Educator explained,

“You know the government programmes have been there for people

with disabilities, they are supposed to benefit, but the truth is I don't have any data that they are, or that there are people who are suffering from Lymphatic Filariasis who have benefited from these services. They need specialised attention”.

Other participants highlighted that government-supported disability services would be beneficial – particularly if they could be bought closer to the community or if patients could be provided with economic and transport support (subsidised) to attend.

Coordination

- Participants suggested that good coordination that linked the various levels of the health system and supported referrals was important in facilitating access to care. Several participants highlighted the need for collaboration with local leaders, community-based organisations and international non-governmental organisations (INGOs) with a local presence to strengthen such mechanisms. A senior nursing officer explained how good coordination could support the patient’s experience and facilitate care,

“The patients with these condition often get news of the management plan through the Village Health Teams, church news, or radio announcements. They often coordinate with their nearest Village Health Team who register them and schedule an appointment with a specialist. Then the caregiver, and usually an NGO or St. Joseph Hospital, can arrange for transport for the patient to a surgery theater at the hospital... Charity organisations such as AYINET [African Youth Initiative Network] have greatly assisted patients with management, providing things like soap, transport to health facility and paying for their hospital bills”.

Recommendations

1. Messaging around the cause of LF and mode of transmission will be beneficial for the reduction of stigma and stigmatising behaviours – particularly the message that LF chronic conditions are not ‘catchy’. Messaging should focus around the already most popular cause (mosquitos) and the commonly-used local words for LF. Separate campaigns for lymphedema and hydrocele could be considered because people generally named one/other symptom rather than them both.
2. A consistent barrier seems to be the availability of services in areas local to the problem because of the cost, pain and logistical elements of transport and accompaniment. The programme should be designed with this in mind. All

services that can be taken direct to the user should be. Consider using already existing platforms: VHTs for outreach, education on hygiene and wound management and provision of low-cost items, such as soap. Training VHTs is essential.

3. Rather than focusing on a referral system, a large-scale awareness effort around basic management of lymphedema should be undertaken. Simple interventions, such as washing and elevation of limbs and proper wound management, are well within the capacity of local health facilities and VHTs. On the part of people living with LF, the campaign should highlight that there are cheap and easy treatments that will really improve quality of life, particularly the reduction of pain and getting back to work. These were the two strongest impacts which people mentioned and so a focus on these will likely have the biggest uptake response. On the health care side, providers need to be sensitised to the potential of these interventions, to advise for their uptake and be able to demonstrate how to do them correctly, and also to provide more positive messaging to those with these conditions about the significant positive impacts this can have on their lives.
4. For surgery: localising this – at least in the short term – could be considered, for example, travelling camps where surgery is free and transport is reimbursed on arrival. Equally, if a referral mechanism is used for integration into routine health care a mechanism of facilitating transport during referrals would be extremely beneficial, as well as providing the surgeries free of charge or heavily subsidised. A retraining for surgeons could be considered, with surgeons encouraged to do home-based follow-ups, to determine recurrence rates.
5. District planners need to be facilitated to be informed about the burden, both in terms of numbers and also the high morbidity impacts on those affected. Dissemination of this report can be a first step but other mechanisms need to be considered – for example, case finding teams (during MDA, for instance) or registers of those suffering from morbidity would be useful. This should definitely be done before plans are made to deploy surgery camps, or similar.
6. Involvement of people living with the conditions could be a useful tool, and FGD participants did indicate enthusiasm for this. Patient advocacy can be a powerful tool in encouraging surgery uptake, MDA uptake, and forming a supportive network. Additionally, undertaking positive deviance exercises could support people in establishing and maintaining morbidity management routines in low socio-economic status settings.
7. Existing capacity should be built upon in all instances: including a full register of health facilities that can perform hydrocele surgery and support for them to do so.

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