



Lymphatic filariasis in Uganda: Knowledge, attitudes and practices Research Summary

October 2020

Introduction

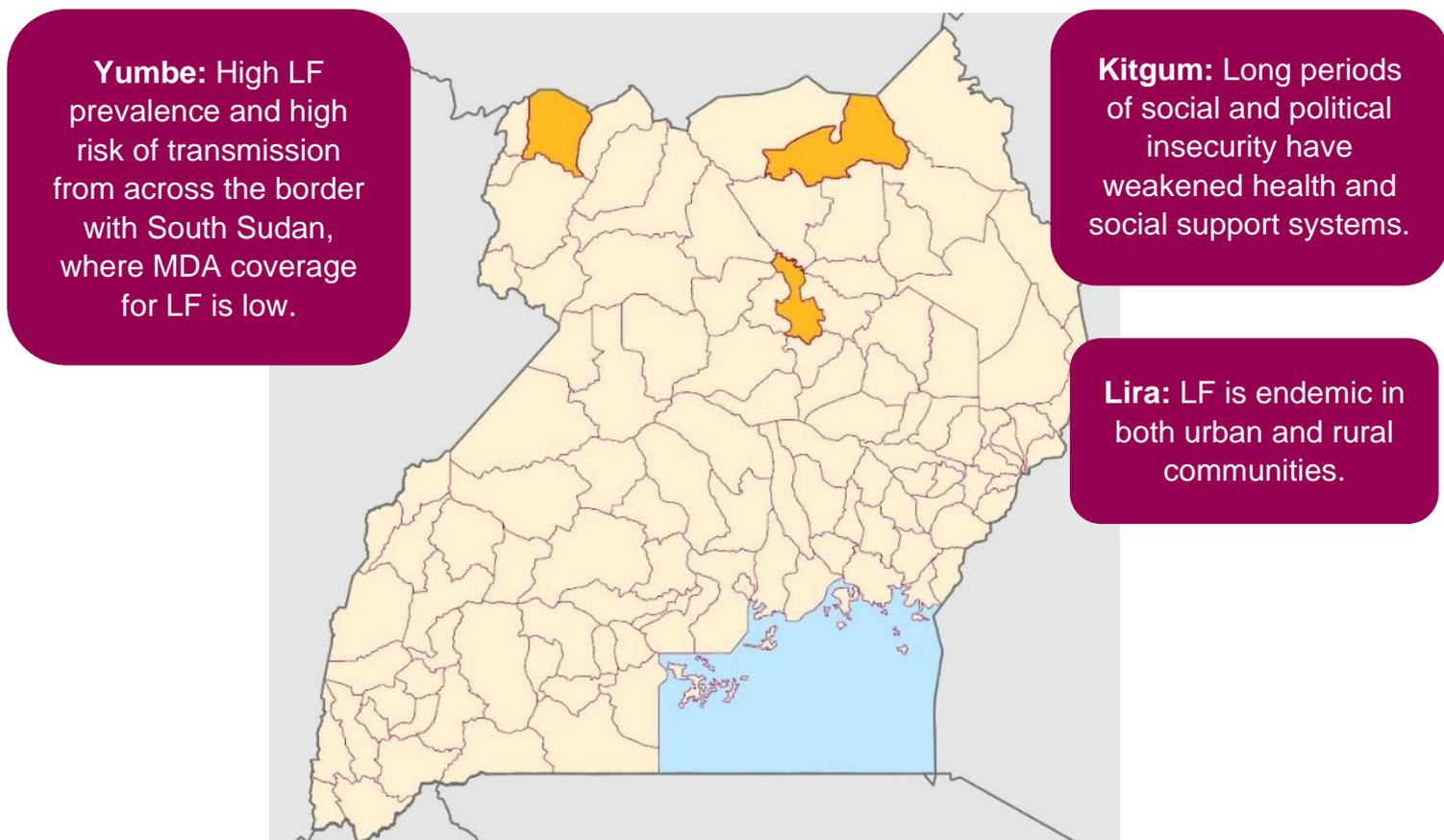
Lymphatic filariasis (LF) is a neglected tropical disease (NTD), spread through the bite of infected mosquitoes. Poor communities in rural areas are the worst affected. Chronic symptoms of the disease tend to develop many years after an individual has been infected as a result of damage to the lymphatic drainage system. Symptoms include inflammation of the skin, elephantiasis of limbs and hydrocele (scrotal swelling). Mass drug administration (MDA) programmes distribute treatments for specific diseases to large populations. In the case of LF, MDA reduces and eventually eliminates transmission, but people who have already manifested symptoms require access to additional surgery and/or morbidity management and disability prevention (MMDP) services.

In **Uganda**, the Programme to Eliminate Lymphatic Filariasis (PELF) has implemented the WHO recommended elimination strategy. It focused on an annual MDA campaign and Indoor Residual Spraying (IRS) to kill mosquitoes, administered across all endemic communities, as well as implementing a Morbidity Management and Disability Prevention (MMDP) approach to alleviate suffering from both the physical and psycho-social consequences of the disease. There has been notable success within the MDA programme in reducing the overall prevalence of LF infection, but implementation of the approach to MMDP has been less of a priority. Little is known about the burden of psycho-social consequences of LF in Uganda, or about knowledge, attitudes and practices around disease prevention and management.

In 2017 the Ministry of Health (MoH) - supported by Sightsavers - conducted a study of the MMDP approach to LF in Uganda using quantitative and qualitative methods. They conducted a quantitative survey of 1,890 households in 90 communities in three regions of the country. The qualitative component involved six focus group discussions and 67 key informant interviews. Participants in the qualitative component were people with LF-related conditions, 'community leaders, religious leaders, leaders', health workers and programme implementers.

The study explored perceptions and experiences of LF, its impact and burden, patient health-seeking behaviours, support and advice offered to patients, and various aspects of health system capacity, planning and management, including the identification of opportunities to improve health service structure and delivery.

Figure 1. Map showing the regions of Uganda that were studied



What do the research findings tell us?

Key messages

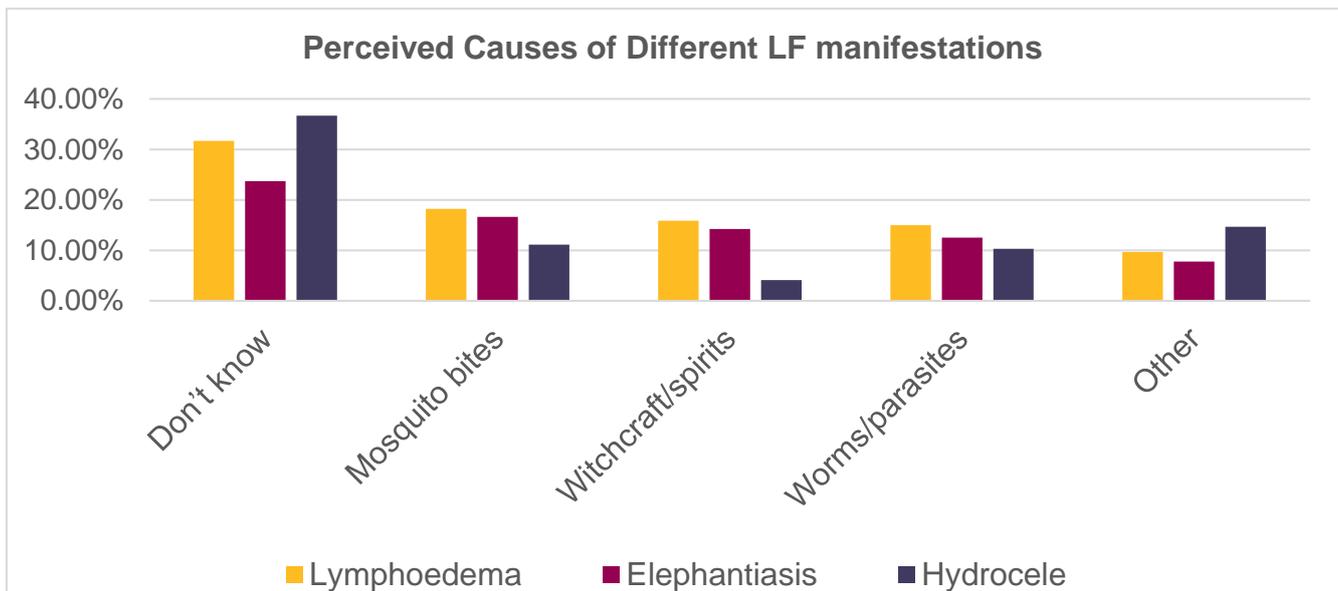
- The burden of LF may be underestimated. **Lack of accurate information on the prevalence of LF-associated conditions in the districts or facility catchment population impedes health planning, management and outreach processes for LF.**
- Insufficient capacity - together with perceptions and experiences of poor care at health centres, particularly in rural areas - discourages treatment seeking at facilities
- Stigma can lead to feelings of isolation and abandonment and can deter people from seeking health care.

The burden of LF may be underestimated. LF was well known in local languages as 'apim', 'longo', 'muringa' or 'ewapa', but it was no longer considered a common condition. The decline in cases was often attributed to successful prevention measures and community sensitisation programmes. However, the burden of LF may be underestimated due to low numbers of affected people presenting at health facilities and limited data collection on

incidence in communities. Districts have begun to try to counter this, for example, through village health teams (VHTs) who are trained to identify and refer chronic conditions during MDA - though resource constraints threaten the sustainability of these initiatives.

Participants indicated that LF was much more common in rural areas. This was linked to greater environmental, behavioural and infrastructural risk factors in rural compared to urban areas. These included less exposure to health education, inadequate health facilities, poor housing, greater exposure to mosquito breeding sites, and the negative influence of traditional health beliefs on health-seeking behaviours and the management of conditions.

Signs and symptoms of LF infection were well known, but the causes of transmission were not well understood. A high proportion of respondents had observed LF and its associated conditions, and could recognise common signs and symptoms. However, knowledge of the primary causes and transmission vectors for infection were relatively low across all study sites: approximately 20% of respondents within each region correctly identified that the cause of LF was worms/parasites and that mosquitoes were the main mode of transmission. Supernatural powers were cited by many respondents as a primary source for both cause and transmission of LF.



Few participants had received advice from health services about how to care for lymphoedema. Many respondents reported caring for their affected limbs as best they could; some reported washing the affected areas to keep them clean. However, few people had received advice from health services and felt there was nothing they could do beyond administering pain relief and using local herbs. Even among patients who had received advice, inaccessible and unaffordable supplies made following management strategies difficult.

Distance to health centres, cost and lack of awareness contributed to delayed treatment seeking. Most commonly found among the rural poor, LF contributes to economic stress by reducing earning potential while requiring higher expenditures on healthcare and medicines. Poverty, lack of awareness and stigma all contributed to patients delaying treatment seeking at health centres until the severity of the condition had a major impact on their life. Once conditions became severe, travel was more difficult and often necessitated

someone to accompany patients to health centres. People also struggled to raise or borrow the funds to travel to health centres.

Many people described frustrating experiences at health facilities. Many health centres were reported as being understaffed, disorganised and inefficient: misdiagnoses were given, patients were advised that nothing could be done, doctors were often absent at arranged appointment times and referrals were given that required long travel times. For patients, this meant long waiting times, unclear and complicated referral procedures, and feeling neglected by health teams. Poor morale among healthcare workers who felt overworked and undercompensated also had a negative influence on the quality of care provided.

Local health centres often lacked the knowledge and resources to accurately diagnose and manage LF. Some local

and community level health staff, VHTs and outreach workers had general training on neglected tropical diseases that was helpful, but they had not received specific training on the identification and management of LF and associated conditions. Patients were referred to higher level health centres, but these were inaccessible to people in rural areas whose LF conditions limited their ability to travel.

“I went to the hospital twice; I can’t be helped. This time I am too weak to go to the hospital.”
- Participant with lymphoedema/elephantiasis

The lack of curative therapies for LF conditions reinforced the sense that seeking care at health centres was futile. Disease and pain management advice given by health workers was often limited to medications to reduce pain and inflammation and prevent infection or sometimes advice on at-home management. However, management strategies could only be adhered to if patients were given the advice and had access to supplies such as medications, soap and dressings. Lack of management advice from health workers - coupled with frequent supply and drug shortages at health centres - meant many patients lacked trust in these services and sought traditional herbal solutions as an alternative.

Strategies to influence positive healthcare-seeking may not reach people in greatest need. Health education outreach and sensitisation efforts have helped to address knowledge gaps concerning prevention and available management and treatment options in affected populations: awareness of symptoms and where to go for help was very important in encouraging attendance at health centres. VHTs identified and referred people with LF conditions and this had a beneficial impact on seeking healthcare. However, sensitisation efforts did not reach all communities, and in some areas people were more likely to seek out traditional forms of healthcare - especially when health services were unable to offer hope of a cure or good, sustainable management options.

Stigma leads to feelings of isolation and abandonment, and can deter people from seeking healthcare.

LF sufferers often experienced isolation due to the physical limitations of the condition and community fears about contagion. Individuals with LF may be physically unable to engage in everyday activities in their homes and communities. Their participation in the community may be further limited by demands that they

“...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.”

do not share communal meals, chairs or spaces. Physical symptoms - as well as clothing and shoes worn to accommodate these - were stigmatised and mocked. LF sufferers said they were more likely to be viewed as lazy and untrustworthy as time went on, making it harder for them to get help or borrow money. Fear of stigma also led to significant delays in people seeking healthcare as they attempted to hide their condition.

Internalised stigma contributes to social isolation and poor mental health. LF conditions have a significant impact on a person's productivity. This was particularly true for people living in rural areas who were dependent on agriculture and construction. The challenges in undertaking work were compounded by difficulties travelling to and from employment. Beyond making physical labour difficult, engaging in physical labour - particularly during cold seasons and cool times of the day - could exacerbate the condition(s).

LF sufferers worried that they could not fulfil familiar and social obligations, such as paying for their children's schooling or maintaining a sexual relationship with their spouse. They feared that their loved ones would leave them. Men with hydrocele were particularly concerned about their wife leaving if they could not produce and support a family. Individuals with LF conditions also worried that they were burdening their family and friends. Depression and low self-esteem were frequently associated with LF.

Uncertainty negatively impacts mental health. Lack of awareness and knowledge about diagnosis, treatment and management options had left many with LF in a state of uncertainty and hopelessness. Even with a diagnosis and prescribed treatment and management options, uncertainty around access, availability and payment caused stress and anxiety. For some, the pain, stress, depression and hopelessness became so severe that they hoped for death. Many participants also reported that their faith helped them come to terms with their condition. The role of religious faith in the lives of people with LF warrants further research.

Implications for policy

Address gaps in individual and community understanding of LF risk and transmission

LF signs and symptoms are often recognised, but common understanding of the way in which the disease is transmitted, and its associated risks, is largely lacking across endemic communities. This is particularly important for remote areas where awareness of simple guidance for disease and care management remains scarce, and where traditional health beliefs are often more prevalent. Developing clear, contextually relevant communication and educational tools around LF transmission, and partnering with community gatekeepers and networks to deliver and champion this messaging, can help to change understandings and increase awareness related to disease risk and prevention practices.

Respond to stigma related to LF to build inclusive health services

Physical limitations restrict work and livelihood opportunities, especially for those living in the poorest areas, straining personal and community relationships. Fear of stigma and community isolation as a consequence of LF plays a significant role in health-seeking behaviours. Traditional healthcare, which may not offer suitable therapies for LF, is often sought instead of more formal settings. Building awareness among health workers around the nature and impact of stigma experienced by LF patients can help to mitigate the experience and anticipation of stigma in facilities. Identifying participatory approaches that

can bring together health workers and patients to share and discuss fears, concerns and challenges related to the disease can facilitate a focused patient-centred approach to healthcare planning and delivery.

Strengthen health provider capacity to diagnose and manage LF patients

Facility staff need to be provided with relevant knowledge and skills to care for LF patients, especially those in more basic, resource-limited health posts. Specific training on identification and management of LF and the associated conditions needs to be focused across all facilities in endemic communities to strengthen local capacity to better manage patient care. Moreover, ensuring health facilities are adequately stocked with appropriate medication and care supplies for LF is crucial to ensure the delivery of quality care, and to encourage patient-provider trust. Evaluation of supply-chain mechanisms should be undertaken to determine where gaps are evident, and opportunities to address these should be identified at all levels of the system.

Improve local service delivery and coordination mechanisms to extend service delivery

Close-to-community service provision is important to facilitate seeking and receiving care for LF patients, especially in rural areas, where the disease risk is high and access to healthcare is limited. Localised service delivery such as village health teams (VHTs) and surgical camps play an important role in identifying, managing and treating LF and its associated conditions, though current resource constraints threaten the sustainability of this network. Supporting these services through increased capacity for funding, training and improved health worker morale needs to be considered to improve and expand programme reach, efficiency and staff retention.

Improve knowledge of disease burden to facilitate planning of health services

Accurately measuring the number of individuals with LF across endemic communities is crucial to inform targeted planning of healthcare services. The true burden may be underestimated due to few people seeking care at health facilities, and limited data collection on prevalence in communities. Increasing community case-finding strategies can help to better capture and record individuals living with LF who may be missed by current facility-based surveillance, and facilitate a more focused approach to health planning, management and outreach work.

Learn more about this area of research

- Read our blog about using participatory research methods to understand experiences of LF [here](#).
- Read about our related work in Nigeria [here](#).

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