

The role of non-governmental development organizations in the implementation of lymphatic filariasis programmes

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The Lymphatic Filariasis (LF) Non-governmental Development Organization (NGDO) Network was established to engage in supporting both international and national LF elimination agendas covering areas such as assisting ministries of health as an on-the-ground link between communities and programmes, which additionally gives the Network members an important voice from the field at international meetings; playing key roles in programme evolution (especially helping to both scale up and scale down mass drug administration [MDA] as elimination thresholds are met); having a role in operational research and developing new programme delivery models that can be taken to scale (such as linkages with other disease programmes and approaches to morbidity management and disability prevention); developing advocacy and policy approaches with other partners; convening other important stakeholders (academic, technical, programmatic and funding); mobilizing financial and technical resources to support programmes; supporting national human resource capacity building to catalyse national ownership of LF programmes; providing leadership in LF governance structures and working in areas of conflict to ensure that everybody in LF-endemic areas enjoys treatment services. Three case studies will illustrate the roles identified for NGDOs in LF programmes covering development of operational research, policy and advocacy linkage between LF and malaria programmes; launching LF morbidity management projects and NGDO's ability to work and deliver LF services in areas of conflict. In addition, the case studies will show the role of NGDOs in mobilising financial and technical resources that support national human resources, leading to national ownership of programmes. Conclusions will be drawn on the role of NGDOs in the Global Alliance for LF elimination and the need for continued partnerships to reach programme goals.

Keywords: LF, malaria and partnerships, MDA, MMDP, network, NGDOs.

Introduction

In 1997, lymphatic filariasis (LF) was endemic in 73 countries, infecting 120 million people, with 44 million persons having elephantiasis, lymphedema and genital pathology.¹ The World Health Assembly adopted Resolution 50.29 in 1997 that called for the elimination of LF as a public health problem. The two pillars of the initiative were annual mass drug administration (MDA) to stop transmission of the infection and morbidity management and disability prevention (MMDP) for those suffering manifestations of the infection. The World Health Organization (WHO) launched the Global Programme to Eliminate Lymphatic Filariasis (GPELF) in 2000.² To support these initiatives, non-governmental development organizations (NGDOs), which were involved in work on LF and/or onchocerciasis programmes, have played a role in advocacy and policy activities that have been essential to the success

of the global effort to eliminate LF.³ This wider partnership, that later evolved to become the Global Alliance to Eliminate Lymphatic Filariasis (GAELF, www.gaelf.org), includes the ministries of health (MOH) of the endemic countries, academic institutions, research organizations, NGDOs, international development agencies, the private sector and donors.^{3–5} The GAELF's mission is to support the GPELF.

NGDOs established the LF NGDO Network (the 'Network') in 2004, following the model of the NGDO Coordination Group for Onchocerciasis Control that had existed since the early 1990s,⁶ to provide a common voice from the NGDO community to the wider GAELF partnership and the GPELF. At the country level, NGDOs play a key role in advocating for establishing national policies and assisting MOHs in implementing their LF elimination programmes.⁷ In particular, NGDOs have successfully advocated for national policies and strategies for MMDP, especially care of

lymphedema and training for hydrocele surgery, and the integration of LF programmes with other initiatives, such as malaria.

NGDOs support a growing network of community drug distributors (CDDs) through national programmes by supporting training and supervision; have a direct role in assisting MOH MDA and morbidity management activities; conduct operational research to improve programme delivery models; bring partners (academic, NGDOs, programmatic and donors) together; mobilise financial and technical resources; build capacity of country MOH programme staff and work to ensure that no one is left behind (e.g. access to LF programme services for people with disabilities or to MDA for those who live in areas of insecurity or conflict).⁸

In Africa, NGDOs utilised a footprint of onchocerciasis ('river blindness') MDA programmes to scale up LF work. For example, Sightsavers changed their royal charter in 2009 to include the treatment of non-blinding neglected tropical disease (NTD) conditions, which resulted in the organisation supporting 45.1 million LF treatments in 2018.⁹

Today the Network, with 30 members, has the aim of facilitating integration and collaboration among NGDOs to support LF elimination. The Network is a platform for information sharing, collaboration and communication, providing technical input on tools, resources and guidelines to national programmes, conducting innovative operations research and lending a common voice from the NGDO community to the GAELF and GPELF.¹⁰

Case studies

Three case studies will illustrate the roles played by NGDOs in LF programmes covering development of operational research, policy and advocacy linkage between LF and malaria programmes, the review of an LF morbidity management project and the work of NGDOs on the 'leave no one behind agenda', including the ability to work and deliver services in areas of conflict. In addition, all the case studies will illustrate the role of NGDOs in mobilising financial and technical resources that support national human resources, leading to national ownership of programmes.

Case study 1: linking LF and malaria programmes

LF in rural Africa is transmitted by the same anopheline vector that transmits malaria. Since 2003 The Carter Center (TCC) has worked with the Nigeria MOH to foster a collaboration between the national LF and malaria programmes at the federal, state and local levels.

Insecticide-treated bed nets (ITNs) for the control of malaria, provided by the Nigerian Federal MOH with global partners for many years, helps recipients avoid mosquito bites that transmit both malaria and LF, thus benefiting both programmes. The importance of ITNs to the LF programme was most pertinent after Nigeria changed its policy of providing ITNs only to 'vulnerable groups' (pregnant women and young children) to one of ITNs for entire populations.

Operational research by TCC, the Centers for Disease Control and Prevention (CDC) and the Nigerian Federal MOH in 2004 showed that CDDs distributing ivermectin and albendazole (MDA for LF) could also distribute ITNs. In the study, >57 000 bed nets were delivered directly to households during one MDA treatment

round, increasing ITN coverage by nine-fold without adversely affecting treatment coverage.¹¹ There were challenges however; CDDs needed about 30% more time to incorporate ITNs with the MDA process, and transporting the bulky nets to villages was much more difficult than that required for the transport and distribution of tablets. However, the experience provided proof of concept for providing ITNs during LF MDAs in Africa.

TCC and its MOH partners launched additional operations research that it hoped might resonate with both the LF and malaria communities. It was demonstrated to the malaria community that LF MDA logistics at the community level could be used to rapidly attain the target ITN coverage and then maintain that high coverage through annual house-to-house assessment of the condition of ITNs and the household's needs during subsequent MDAs. For the LF community, operations research demonstrated that ITNs were synergistic when added to MDA in achieving LF transmission interruption and helped LF share some of the considerable political support enjoyed by malaria.¹²

TCC also worked with MOH colleagues to demonstrate that ITNs alone could be used to block LF transmission in areas co-endemic for *Loa loa* infections, where ivermectin-based MDA could not be used for fear of drug-related adverse events.¹³ Integrated LF-malaria health education messages were found to be attractive to both malaria and LF communities. Young men who rejected the use of ITNs suddenly changed their minds when they learned that ITNs would protect them from filarial hydrocele.

The former Head of State of Nigeria, General Dr. Yakubu Gowon, and his Gowan Center, have long collaborated with TCC, beginning with the successful MOH Nigeria Guinea Worm Eradication Programme. In 2012, TCC co-sponsored a meeting with the Gowan Center and the Nigerian Federal MOH to explore the shared opportunities between the national malaria and LF programmes. The conference concluded that increased collaboration between LF and malaria programmes had the potential to accelerate coverage of interventions for both diseases, while at the same time realizing cost savings for each programme. General Dr. Gowon concluded the meeting with the statement, 'I will never say the word 'malaria' again without also saying 'elephantiasis.' The two must go together!' A technical working group was established to promote malaria and LF collaboration. In 2013 the Nigerian Federal MOH published a policy guideline for co-implementation.¹⁴

Case study 2: supporting LF morbidity management

One of the two core LF elimination strategies is to alleviate the suffering caused by the disease through provision of a morbidity management package to manage lymphedema and hydrocele.^{1,2} While the MDA pillar for LF elimination was attractive to donors and rapidly scaled up, the morbidity management component lagged behind, with less funding and generally poor implementation in endemic countries.^{15,16}

Helen Keller International (HKI) led a 5-year (2014–2019), \$35 million MMDP project funded by the US Agency for International Development (USAID).¹⁷ This project provided technical and programmatic assistance to Burkina Faso, Cameroon and Ethiopia to improve capacity to provide high-quality surgery and disease management services for people suffering from trachomatous trichiasis, filarial hydrocele and lymphedema from LF

and podoconiosis. The initiative also supported the global community's MMDP needs relating to human capacity strengthening, monitoring and evaluation and partner coordination. The specific objectives included to strengthen MMDP data availability and quality for decision-making at the country level, to strengthen support for MMDP implementation scale-up and quality improvement, to strengthen the capacity of MMDP systems and to provide MMDP best practices and policies.

For the LF component of the project HKI collaborated with partners such as the WHO, GAELF, RTI International, African Filariasis Morbidity Project, CDC and universities to bring together LF expertise to guide the implementation of the project.¹⁸ By documenting lessons learned, investigating promising practices and sharing knowledge widely, the MMDP project improved data availability and use, filled gaps in the LF knowledge base, contributed to operational research and developed a range of tools and resources for LF MMDP MOH programmes to implement (Box 1).¹⁹

Box 1. List of LF MMDP tools developed through the MMDP Project

Filaricel Surgery Training Package
 Procurement Calculator for Hydrocele Surgery
 Filaricel Anatomical Surgical Task Trainer Simulator: Manufacturing Manual
 Procurement Calculator for Lymphedema Management
 Lymphedema Management Video
 Lymphatic Filariasis Patient Identification Job Aid
^aThe tools are available from Helen Keller International.¹⁹

The project strengthened health systems to improve morbidity management by assessing the capacity of health facilities, procuring necessary equipment and supplies, training surgeons and other healthcare providers and improving data management systems. The project trained 4807 people and provided 2100 hydrocele surgeries along with 2148 patients trained for self-care.¹⁸

Case study 3: working in areas of conflict and the concept of leaving no one behind

There has been good progress towards the LF elimination goal. However, LF in areas in conflict remains a challenge in starting MDA or reaching elimination targets. This challenge could derail the verification of elimination in many countries unless approaches are identified to work in such environments.²⁰

Sightsavers and partners lead the Accelerating the Sustainable Control and Elimination of Neglected Tropical Diseases (ASCEND) West and Central African programme (an integrated NTD programme) funded by the UK Department for International Development. During the inception phase, 13 programme countries identified strategies to promote the delivery of inclusive NTD treatments and services, including LF, to people in danger of being left behind. When developing the strategies, MOH country teams were encouraged to define those at greatest risk of being 'left behind' in their context and then plan to minimise barriers to access. Special focus was placed on people with disabilities and the promotion of gender equity. In some countries a key element

of this process was to include refugee and internally displaced communities and those living in areas that were difficult to access because of insecurity.

Accelerating the Sustainable Control and Elimination

Applying the 'leaving no one behind' agenda in Nigeria meant that the NTD actors (e.g. Sightsavers and HKI) liaised with security agencies, not one of the usual partners in NTD programmes, which enabled the delivery of drugs to those residing in six insecure local government areas of Borno State. This was a notable achievement, as no MDA had taken place in these areas for 6 years prior to 2019 due to the Boko Haram insurgency.

Conclusions

It is generally recognized that in most LF-endemic countries, MOHs and national health systems are underresourced financially and in terms of logistics and capacity. NGOs play an important role in identifying these gaps specifically pertaining to LF and supporting MOH LF programmes to fill them as implementation partners. As a result, members of the Network have played a key role in scaling up programmes and in supporting safe stopping of MDAs and post-MDA surveillance using the WHO Transmission Assessment Survey approach. The Network has also supported scaling up and sustaining morbidity management programmes. This has helped a number of countries (e.g. Togo and Malawi) achieve the ultimate goal, WHO verification of elimination of LF as a public health problem. Beyond the roles its members play in supporting country programme implementation, the NGOs have pioneered new areas of operational research, advocacy and policy development to be shared at the national and international level, as shown here with the example of integration of malaria and LF activities.

One in five of the world's poorest people has a disability.²¹ People with disabilities are at significant risk of being excluded from many development programmes and interventions, including health. LF programmes cannot yet be considered as beacons for inclusion. The push to eliminate transmission of LF through preventative chemotherapy could lead to the neglect of long-term morbidity management and a lack of measures to improve the mental health and well-being of those impacted by NTD-related morbidity or disability. With the progress of LF elimination in each country, NGOs will continue to advocate for national policies and strategies for disease surveillance and, in particular, to advocate for and provide support for continued provision of care for patients with LF morbidity at health facilities.

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