

Keeping communities at the centre of efforts to eliminate lymphatic filariasis: learning from the past to reach a future free of lymphatic filariasis

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Since the launch of the Global Programme to Eliminate Lymphatic Filariasis (GPELF) in 2000, more than 910 million people have received preventive chemotherapy for lymphatic filariasis (LF) and many thousands have received care for chronic manifestations of the disease. To achieve this, millions of community drug distributors (CDDs), community members and health personnel have worked together each year to ensure that at-risk communities receive preventive chemotherapy through mass drug administration (MDA). The successes of 20 y of partnership with communities is celebrated, including the application of community-directed treatment, the use of CDDs and integration with other platforms to improve community access to healthcare. Important challenges facing the GPELF moving forward towards 2030 relate to global demographic, financing and programmatic changes. New innovations in research and practice present opportunities to encourage further community partnership to achieve the elimination of LF as a public health problem. We stress the critical need for community ownership in the current Covid-19 pandemic, to counter concerns in relaunching MDA programmes for LF.

Keywords: community, community participation, lymphatic filariasis, mass drug administration.

Introduction

Since the launch of the Global Programme to Eliminate Lymphatic Filariasis (GPELF) in 2000, more than 910 million people have received preventive chemotherapy for lymphatic filariasis (LF) and many thousands have received care for chronic manifestations of the disease.¹ These two pillars form the basis for the global drive to eliminate LF as a public health problem and to reduce the cycle of poverty that LF brings to households and to communities.^{2–4} For GPELF to reach its goals to deliver treatment and reach affected individuals, millions of volunteers, health workers and community members in endemic countries are mobilised each year to deliver donated medicine and to identify and care for affected individuals. Many of these communities are on the ‘last mile’: geographically isolated and underserved, where people live in the most vulnerable circumstances. This periodic treatment of at-risk populations with donated medicines, or mass drug administration (MDA), provides treatment for persons with

asymptomatic LF infection, reduces early-stage chronic disease manifestations and is effective against intestinal helminths. Beyond the physical benefits of treatment, the economic benefits to individuals, households and communities who have eliminated LF are substantial.^{5,6}

To date, 14 countries have received validation by the WHO as having eliminated LF as a public health problem and are under surveillance.¹ These efforts have reduced the estimated number of individuals requiring MDA by 597 million. Despite these impressive gains, MDA must be continued for 893 million people in 49 countries.^{1,7} With the launch of a new WHO neglected tropical diseases (NTDs) roadmap in 2020,⁸ the time is right to review the lessons learnt over the last 20 y and apply them to the next 10 y when LF elimination as a public health problem must be secured. We reflect here on the key role that communities play in ensuring the success of the GPELF as well as examining some of the challenges and innovations available to address them.

Learning from the past

Much of the success of the GPELF can be attributed to the engagement and participation of people living in endemic communities. From the beginning of the programme, the need to engage communities for MDA to work was clear.^{9–11} An early study conducted in Ghana, Kenya, India, Myanmar and Vietnam suggested that mechanisms for community drug delivery differed between these countries. African study communities preferred to select drug distributors from their communities to deliver MDA, while in India an approach with formalised health staff was more readily accepted.^{12,13} Throughout the 20 y of the programme, the design of MDA has varied between countries in Asia and Africa. An advantage in the African context was that many LF-endemic communities had experienced MDA for onchocerciasis delivered through a community-directed platform (community-directed treatment with ivermectin [CDTI]). In CDTI, communities were responsible for selecting and supporting their community drug distributors (CDDs) and deciding on MDA timing.¹⁴ These parameters formed the basis for MDA in sub-Saharan Africa. In India and Indonesia, two of the countries with the highest LF burdens in the world, a combination of formal health workforces and subsidised community health workers (Ashas, Aganwadi, kaders) were engaged in the MDA, working together to deliver treatment. In all of these settings, the CDDs needed to be honest, trustworthy and known members of their community.^{15–17} Much research has highlighted that CDDs were motivated by community recognition, improved self-esteem, an opportunity for personal development and care for their communities, rather than by cash incentives.¹⁸ This is remarkable in light of the significant opportunity costs these individuals incurred in their work.^{19–21}

Regardless of location, community engagement in MDA assured greater success. Communities provided financial and human resources to support the rollout of MDA. Community engagement increased awareness about the value of LF elimination for the whole community, which, in turn, was associated with coverage.^{22,23} Community leaders demonstrated that the tablets were safe to take, by being the first to swallow tablets during launching ceremonies. Community engagement strategies that were developed with a partnership approach supported and sustained the political commitments needed for LF elimination to succeed.¹⁵ Furthermore, through community engagement in LF programmes, community members increased overall health literacy about vector control, hygiene and care for individuals with lymphedema and other health issues.

LF MDA has served as a community platform for healthcare. The CDTI model, adapted for LF, demonstrated the potential to strengthen primary healthcare services, particularly in rural and disadvantaged areas.^{24,25} CDDs, whether trained under CDTI for onchocerciasis or in MDA programmes for LF, applied their skills to other health programmes in their communities.^{26,27} MDA has improved trust in overall healthcare delivery among marginalised communities, counteracting some of the effects of social exclusion, even creating a platform for improved human rights.^{28,29} LF has been integrated with other initiatives that improve community healthcare. The LF transmission assessment survey has been used to understand the distribution of other infections, demonstrating the feasibility of incorporating other disease programme efforts.³⁰ Vector control enhances the sustainability of MDA and

reduces infection due to other vector-borne infections like leishmaniasis, malaria and dengue.^{4,31}

Challenges to community engagement with LF elimination

In the 20 y since the start of the programme, the global context has changed dramatically, in terms of financing, demographics and within the GPELF itself. In 2003, the combined term ‘neglected diseases’ was used in a WHO meeting held in Berlin.³² At this time, the LF and onchocerciasis programmes were frequently independently managed within the Ministry of Health. Now in 2020, 20 y later, most national programmes integrate multiple NTDs (including LF) into one programme. While integration has afforded many benefits to programmes and communities in terms of increased resources and expanded partnerships, it has also disrupted the way in which communities were traditionally involved in MDA. Today in most endemic countries, MDA for LF must be completed within a specified number of days to accommodate a full activity calendar and budgetary constraints. This tight timeline has made it challenging to bring communities on board in the same way as under a community-directed approach. Chami et al. highlight this as community-based MDA where communities do not lead the MDA design. For example, in a community-based MDA, communities may select the CDDs, but may not choose the dates, time period or methods of distribution.³³ This shift from community-directed to community-based MDA has had implications for the selection of the drug distributors, the support offered to them from their communities, the timing of MDA, the frequency of household visits during MDA and outreach to individuals absent during MDA.

Since the commencement of the GPELF, another challenge has been the unequal attention given to morbidity management and disability prevention compared to MDA.³⁴ Evidence across geographic areas has demonstrated a link between the two pillars of LF elimination; for example, in communities where care or benefit was provided to LF patients, there was higher coverage with MDA.^{35–37} The global focus on MDA may have missed opportunities to bring communities together around care for affected individuals, which would in turn reinforce the need for MDA.

Globally population dynamics are changing due to climate change, conflicts and economic migration. There are more displaced people today than at any other time in recorded history.³⁸ These shifting demographics have made MDA more challenging in terms of knowing the number of people requiring MDA and reaching people. Urban migration in search of better economic prospects has created fragmented and expansive urban landscapes where people tend to live more independently and may be less motivated by social good to participate in LF elimination. Urban MDA remains a major challenge to LF elimination.^{37,39–41}

The Covid-19 pandemic presents new challenges to community engagement for LF elimination. Reports of stigmatisation and harassment of healthcare workers and community members have been reported as communities react with panic and fear to the spread of the pandemic.^{42,43} Disruption of regular healthcare services has resulted from lockdowns that prohibit population movements or from fear of contracting Covid-19 at health

facilities.⁴⁴ The urgent nature of the pandemic has meant that NTD personnel have shifted their focus to the Covid-19 response, as have the thousands of CDDs enlisted to help their own communities.⁴⁵ As Molyneux et al. suggest, to address some of the challenges posed by Covid-19 for LF elimination programmes, we can learn from the experiences of the resumption of health programmes after suspensions due to Ebola virus disease (EVD).⁴⁵ In this context, purposive pre-MDA assessments of community beliefs and perceptions about MDA,⁴⁶ as well as dedicated forums for community conversations about the impact of EVD,^{47,48} were helpful in shaping the continuation of health programmes. These examples, and others, can help to bring the voices of the community to the delivery of MDA in the context of the Covid-19 pandemic and the postpandemic era.

Moving forward to 2030

Sociodemographic changes during the last 20 y have altered the way people communicate and receive information. The rapid increase of mobile phone use has brought new opportunities for communication in the GPELF. Cellphones are being used to monitor MDA in real time and to record LF cases, in turn helping CDDs feel more empowered and informed.^{49,50} Social media platforms can increase communication for CDDs, supervisors and community members. These technologies provide new opportunities to monitor LF programming, reach community members, support CDDs and provide disability prevention and support. New innovations must continue to be explored even after LF transmission has stopped so that individuals living with LF receive the lifelong care and support they need to prevent further associated morbidities.

New methodologies are being used to better understand community dynamics and to capitalise on existing relationships. Research on network analysis has demonstrated that there are certain individuals within the community who are more 'connected' than others.⁵¹ By identifying those individuals and harnessing their ability to reach people through their existing networks, MDA programmes can reach more community members with information and treatments.⁵²

Including a gendered perspective in MDA has provided a more nuanced understanding of the roles that men and women have within a community and how these roles might affect uptake with MDA.⁵³⁻⁵⁵ These gendered roles are in constant flux as access to education and technology improves. To uncover potential inequities in MDA and to refine and tailor awareness and outreach activities more effectively, the LF community must first heed increased calls for the collection and use of gender-disaggregated data in MDA programmes.⁵⁶⁻⁵⁸ Furthermore, gender-based analysis needs to be incorporated into the planning and execution of MDA for LF elimination as well as in the care and management of chronic manifestations of the disease.⁵⁷ Gender analysis is also recommended to understand the differential burdens and experiences that CDDs face in their work. This analysis can guide the development of appropriate strategies to improve CDD recruitment, support and supervision. Together, these approaches can help to build more equitable LF programmes.

Finally, the triple drug therapy (ivermectin, diethylcarbamazine citrate and albendazole [IDA]) for LF provides an opportunity to accelerate towards elimination goals.^{59,60} Guided by WHO guidelines, programmes that introduce IDA must review their ex-

isting MDA and ensure quality enhancements to achieve high coverage.⁶¹ This includes a renewed commitment to community engagement, higher levels of participation of government and community leaders, increased time available for MDA delivery and better supervision. Early adopter countries using IDA treatment have purposefully listened to communities to understand what adjustments need to be made to improve their MDA delivery (personal communication, AK). Not only does IDA offer a chance for acceleration towards elimination but it also provides opportunities to increase community ownership by engaging communities in the design to deliver an improved MDA with IDA.

Conclusion

We must acknowledge the crucial role that communities play in achieving the success of any global health programme. We know that without them our efforts will fail. Perhaps now, more than ever in this time of Covid-19, community ownership of LF programmes must be encouraged and reinforced.⁶² With the pandemic, there may be concerns about physical distancing during MDA, internal population movements, provision of personal protective equipment for CDDs and distribution of unpackaged pills. Including the community perspective in relaunching MDA programmes will be critical. We must use this opportunity to embrace new innovations and technologies to improve MDA programmes and ensure community ownership. And we must remain adaptive to changing environments, listening to how communities themselves understand these changes. Communities have proven themselves resilient over time and through challenges from within and without. Harnessing that power and resiliency will only further strengthen the GPELF. We owe it to communities to stay the course on the road towards a future free of LF in 2030.

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