

Neglect in the numbers: leaving no voice behind in disease elimination

For any disease nearing elimination, adding precision to data is a must. In *The Lancet Global Health*, the Local Burden of Disease (LBD) 2019 Neglected Tropical Diseases (NTD) Collaborators have presented geospatial estimates of the global prevalence of lymphatic filariasis at a welcome level of precision, with the aim to identify areas where additional programme investment (data and treatment) might be needed to reach elimination goals.¹ We think a clear direction for investment should be in rethinking disease management, disability, and inclusion (DMDI).

Although progress towards eliminating lymphatic filariasis continues, the DMDI components of elimination programmes are often neglected, a point rightfully highlighted in the Comment by Joseph Kamgno and Hugues Nana Djeunga.² The new NTD roadmap and the elimination dossier both emphasise providing a minimum package of care for patients with lymphoedema and hydrocele as crucial to the validation of elimination targets. In our experience, this DMDI minimum package is not only rarely implemented, but also insufficient in its scope. The current medical management of these conditions fails to address chronic stressors associated with lymphatic filariasis, such as stigma, isolation, and economic hardship,³ and omits mental health as an important component of care. The narrow and vertical focus⁴ of the minimum package can also limit its ability to meet peoples' needs, and fails to capitalise on opportunities for strengthening lymphatic filariasis management by collaboration with other disease programmes, mental health services, and disability and inclusion programmes.

The Global Programme to Eliminate Lymphatic Filariasis was formed in

response to lymphatic filariasis being the second leading cause of permanent and long-term disability.² Clearly, the needs and priorities of people affected by lymphatic filariasis—estimated to be more than 35 million—should be at the centre of health service design and delivery.⁵ A reliance on siloed and verticalised approaches to the provision of care is likely to limit progress towards universal health coverage and impede the attainment of good health and wellbeing for affected people. Papers, such as the one by the LBD 2019 NTD Collaborators,¹ which focus on infection prevalence as the sole measure of elimination, omit the mention of DMDI, and refer to the stopping of programmes upon elimination, unwillingly contribute to the invisibility of those with life-altering morbidity as a result of lymphatic filariasis.

We advocate for an increased focus on implementation research that seeks to understand and address health system barriers to ensuring a holistic continuum of care for people with lymphatic filariasis. Approaches that put people and communities at the centre, recognising them as assets in the coproduction of health and social care, are essential in driving this agenda forward. Data drawn from patient experiences should be given the same weight as projections of disease distribution in decision making regarding disease elimination. This rethinking is crucial for lymphatic filariasis, but also extends to other diseases that are being added to the NTD portfolio. We must avoid making the same mistakes in neglecting to adequately consider the provision of holistic support for affected individuals, particularly those for whom mass drug administration campaigns might come too late.

A focus on people and not diseases, and country-owned systems that reflect the values, needs, and experiences of people affected by NTDs, their households, and communities, are vitally important to ensure that DMDI strategies are truly

person-centred and address avoidable, unfair, and unjust health outcomes for the most vulnerable.

We declare no competing interests.

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- 4 Marchal B, Van Dormael M, Pirard M, Cavalli A, Kegels G, Polman K. Neglected tropical disease (NTD) control in health systems: the interface between programmes and general health services. *Acta Trop* 2011; **120** (suppl 1): S177–85.
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For the French translation of the letter see Online for appendix