

# Understanding the community impact of lymphatic filariasis: a review of the sociocultural literature

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**Abstract** Lymphatic filariasis (LF) is endemic in approximately 80 tropical and subtropical countries. About 120 million people are infected with the parasite and a billion are estimated to be at risk of infection. The main focus of the LF elimination programme to date has been to interrupt transmission by means of annual community-wide treatment campaigns with diethylcarbamazine and albendazole, or albendazole and ivermectin, for a period of four to six years. Although substantial progress has been recorded wherever the strategy has been successfully implemented, initial gains have been accompanied by a realization that this strategy alone will not ensure a permanent solution in all settings. The fairly extensive LF literature is dominated by laboratory research and quantitative field measurement of the impact of LF, particularly local prevalence studies of parasite-infected humans and vectors. As the global elimination programme expands, the absence of sociocultural understanding is being recognized as a critical flaw in ensuring that programmes are appropriate and responsive to local needs and understanding. This paper assesses the current state of sociocultural understanding pertaining to LF. It concludes that, at present, there is insufficient understanding of the sociocultural factors associated with the presence and treatment of the disease, and that appropriate social science methods should be used to address this deficiency and ensure community partnership in delivering and sustaining the success of LF elimination programmes.

Bulletin of the World Health Organization 2007;85:493–498.

Une traduction en français de ce résumé figure à la fin de l'article. Al final del artículo se facilita una traducción al español. الترجمة العربية لهذه الخلاصة في نهاية النص الكامل لهذه المقالة.

## Introduction

Lymphatic filariasis (LF), the second most common vector-borne parasitic disease after malaria, is found in over 80 tropical and subtropical countries. WHO estimates that 120 million people are infected with the parasite, with one billion at risk. These figures are certain to be revised upwards because global prevalence mapping has not yet been completed.<sup>1</sup> According to WHO, LF is the second most common cause of long-term disability after mental illness.<sup>2,3</sup> One-third of people infected with LF live in India, a third live in Africa and the remainder live in the Americas, the Pacific Islands, Papua New Guinea and South-East Asia. While not explicitly mentioned in the Millennium Development Goals, LF and other neglected tropical diseases are recognized in the

report on the Commission for Africa as contributing significantly to the overall African disease burden.<sup>4</sup> LF and other helminthic diseases leave infected individuals, particularly women and children, more vulnerable to HIV/AIDS, tuberculosis and malaria.<sup>5</sup>

LF causes a wide spectrum of clinical and subclinical disease. Approximately two-thirds of infected individuals show no overt evidence of disease, but when tested demonstrate some degree of parasite-associated immunosuppression, and many show evidence of renal dysfunction. The remaining third suffer from the chronic manifestations of LF – chronic lymphoedema, elephantiasis and hydrocele. Further, those infected with LF suffer the debilitating effect of acute filarial attacks that last from five to seven days and may occur two to

three times each year.<sup>1–3</sup> Chronic filarial disease has serious social and economic effects. Those afflicted with elephantiasis and hydrocele are often socially marginalized and poor. Acute attacks and chronic disability cut economic output and increase poverty.<sup>1,3</sup>

In 1997, a World Health Assembly resolution called for the elimination of LF. Public health interventions thus far have focused on interrupting the transmission of the parasite through the use of mass drug administration campaigns (MDAs). The MDA programmes deliver community-wide doses of diethylcarbamazine and albendazole, or albendazole and ivermectin, once annually for a period of four to six years.<sup>3,6,7</sup> Although substantial progress has been recorded wherever the strategy has been implemented, initial gains have been

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doi: 10.2471/BLT.06.031047

(Submitted: 25 February 2006 – Final revised version received: 17 November 2006 – Accepted: 14 December 2006)

accompanied by the realization that an intervention that assumes compliance will not alone ensure a permanent solution in many settings. Even in areas where LF prevalence has been reduced to less than 1% of the population, elimination remains elusive and in some situations the disease has resurged.<sup>8,9</sup> We argue that these “upstream” interventions could deliver more effectively “downstream” at community level if the programmes were more firmly grounded in sociocultural awareness during the planning stages. This paper explores the disparity between the way the disease is defined at the elimination programme planning stages and the way it is defined and perceived in the diverse communities where it is implemented. We describe the impacts of undiagnosed and untreated LF on the lives of potentially active and productive men and women and explore the impact that awareness of local health and sociocultural norms and values can have on improving primary and secondary LF control efforts.

### Impact on infected individuals Current knowledge about LF's sociocultural burden

The chronic manifestations of filariasis can have significant, and often very negative, social impacts.<sup>7,10,11</sup> The chronic disabling manifestations of this disease, including lymphoedema of the limbs, breasts and external genitalia, have a profoundly detrimental effect on the quality of life of affected individuals. The degree of social disability varies between cultural settings, but the degree of stigmatization appears to be directly correlated with the severity of visible disease.<sup>12,13</sup> In conservative contexts, affected individuals avoid seeking treatment for fear of drawing attention to their condition.<sup>13,14</sup> Failure to treat the disease results in recurrent acute febrile attacks and progressive damage to the lymphatic system. Without access to simple hygiene advice, sufferers are unable to prevent further progression of the outwardly visible complications of LF.<sup>15</sup>

Women bear a double burden in societies where much of their role and identity is dependent upon marriage and the ability to give birth to children. Young unmarried women with LF may be forced to lead a reclusive existence in an attempt to hide their illness or because their limited marriage prospects make them a burden to their families.<sup>10</sup> In Thailand and in west Africa there is a general perception that children born to

a woman affected by LF will be similarly affected.<sup>16,17</sup> Shame and anxiety related to difficulties in conceiving children are common for LF patients around the world.<sup>18,19</sup> Young females with LF are considered poor marriage prospects because the disease's recurrent debilitating acute episodes limit their ability to perform paid and unpaid work. The costs associated with long-term health care as the disease progresses result in perceptions of these women as financial burdens.<sup>20–23</sup>

Although women may have concerns about marrying men with the physical stigmata of LF, their gender roles and prevailing power structures often leave them in a relatively powerless position. In Haiti, Coreil et al. found that the risk of dysfunction and unhappiness was greater in marriages where the wife had physical manifestations of filariasis.<sup>24</sup> This is supported by data from coastal Ghana.<sup>20</sup>

Gyapong et al.<sup>25</sup> suggest that the physical and psychological burden borne by men has a negative impact on their marriage and employment prospects. The extent of male sexual disability as a result of LF has not been extensively studied, but investigators believe that there is a significant “silent burden”.<sup>26</sup> Gyapong et al.<sup>25</sup> found that hydrocele had a significant impact on young men, particularly at a time when they were struggling to establish their sexual identity and their capacity to be reliable economic providers. Unwillingness to admit to sexual dysfunction may shroud the real extent of this issue. South American researchers found a wide range of disease-related problems, including marriages without sexual activity, reports of painful intercourse in women whose partners had penile lymphoedema and suicidal thoughts of both male and female partners being attributed to the disease.<sup>26</sup>

### Impact upon lifestyle and economic opportunities

Gyapong et al. speculate that the current estimate of 850 000 disability-adjusted life years (DALYs) lost as a result of LF was a gross underestimate.<sup>25</sup> The estimates are based on an assessment of gross clinical manifestations and do not take account of the “incidence, duration and severity of acute adenolymphangitis”. In particular, the estimate fails to capture the impact of disease on young people who, while

not displaying clinical manifestations or physical abnormalities, may be suffering the effects of acute fever attacks. Acute episodes of adenolymphadenitis may result in school absenteeism and poor educational attainment. Chronic disease can also present in childhood and affect children's quality of life.<sup>27</sup>

As the disease progresses, the individual's capacity to labour, both productively and reproductively, is increasingly hampered. Coreil et al.<sup>24</sup> note that in the Haitian context, while impairment of mobility impacts upon the ability to garden or sell produce in the market, acute attacks are equally detrimental to individuals' ability to support themselves and their family. This finding is echoed by the work of Gyapong et al.<sup>25</sup> and Suma et al.<sup>28</sup> As the disease progresses, the affected individual becomes too severely disabled to contribute to household labour and further burdens the household economy.

### Impacts on the LF elimination programme Paucity of LF-related sociocultural research

A comprehensive literature search was undertaken to identify all published sociocultural information available from LF-endemic countries. It was conducted using PubMed, Ovid and their associated databases. Keywords included: lymphatic filariasis, filariasis, *Wuchereria bancrofti*, *Brugia malayi*, *Brugia timori*, elephantiasis, hydrocele, sociocultural and socioeconomic.

Published LF literature is dominated by laboratory research and quantitative field measurement of the impact of LF, with a wealth of local prevalence studies of parasite-infected humans and vectors. Several researchers have highlighted the dearth of sociocultural information on local beliefs, perceptions and behaviours towards the disease.<sup>24,29,30</sup> The paucity of sociocultural data is a common feature of other neglected tropical diseases. Even with malaria, the neglected parasitic disease with the greatest tradition of sociobehavioural research, Williams and Jones<sup>31</sup> observed that this research, while key to successful outcomes, has yet to realize its full potential in contributing to control. Krishna Kumari et al.<sup>23</sup> and Gyapong et al.<sup>25</sup> have argued that the lack of understanding and documentation of LF's socioeconomic consequences have led to a gross underestimation of its impact. As the global elimination

programme expands, the absence of sociocultural insights and understanding appears to be impeding progress.

The multidisciplinary nature of the social science approach to researching infectious diseases is often poorly understood by disease control programme planners.<sup>32</sup> Fundamental differences in research paradigms, research strategies and even language make qualitative research approaches and findings difficult to communicate.<sup>33</sup> Williams and Jones<sup>31</sup> observed that changing the status quo can be difficult in a context dominated by research and funding structures that are not geared towards sociocultural approaches. The United Kingdom-based Institute for Development Studies notes that "Health research [in the developing context] is often funded by specialised agencies and priorities identified by health sector managers who mostly have medical training."<sup>34</sup> The very tightly focused health research agenda often overlooks or rejects the development of local sociocultural understanding strategies against LF and other infectious diseases.<sup>35</sup>

### Beliefs about disease causality and transmission

Little information has been formally collected about how communities incorporate LF, its origins and impact, into local knowledge systems. The role of mosquitoes in transmitting the parasitic agents of filariasis is poorly appreciated in many endemic communities, and thus it is not surprising that there is little awareness in these areas of the importance of minimizing mosquito contact for preventing infection.<sup>12</sup> In a Malaysian study, only nine of 108 respondents associated filariasis with mosquitoes, while walking barefoot on dirty ground or consuming contaminated food or drink was commonly implicated as the source of infection.<sup>36</sup> In rural Thailand, while schoolchildren indicated correctly that mosquitoes transmit filariasis and that the disease could be prevented by personal protection against mosquito bites, adults maintained that the disease was inherited or resulted from poor blood circulation, carrying heavy loads, prolonged standing, bathing in or drinking swamp water, personal contact with infected individuals or sorcery.<sup>14</sup> Suma et al.<sup>28</sup> found that many participants in the Indian survey believed that the disease was inherited. In Papua New Guinea and the United Republic of Tanzania,

although most people indicated that mosquitoes spread malaria, few understood that mosquitoes could also spread filariasis<sup>18</sup> (Wynd et al., unpublished observation). Ahorlu et al.<sup>37</sup> found that many villagers in a coastal Ghanaian community rejected the mosquito's role in transmission. In French Polynesia, despite an intensive community education campaign, most people discounted the idea that mosquitoes played any part in disease transmission and attributed LF to the act of immersing an injured ankle in the sea or consuming contaminated food and drink.<sup>38</sup>

In the Philippines correct knowledge of disease transmission was associated with the highest level of formal educational attainment.<sup>39,40</sup> A study in rural south India found that only 9% of apparently uninfected people and 20% of patients with chronic filarial pathology knew that filariasis was contracted through mosquito bites. Other causes commonly cited were occupation, polluted drinking water and poor nutrition.<sup>41</sup>

### Community ownership of treatment programmes

Gyapong et al.<sup>35</sup> found that community-directed MDA programmes achieved much higher levels of coverage than those delivered exclusively through the formal health sector and were especially effective in areas where health facilities were limited.

Rifkin<sup>42</sup> has argued that community involvement is more effective when viewed as an ongoing process. The explanation for improved coverage in the Ghanaian context appeared to be twofold. First, the community was more likely to "own" the process because it was involved in directing it and, as a result, was more likely to participate and encourage participation by all community members. It is possible that this sense of ownership may override or soften resistance to outside intervention. Secondly, the iterative approach to seeking permission, returning to train local treatment coordinators and ultimately delivering medication resulted in a higher overall level of understanding of the programme's purpose. Gyapong et al. highlight the need to allow this pilot intervention time to expand into a larger geographical area and to broaden its focus to include other health areas before claiming that the approach has long-term sustainability.

## The value of increasing our sociocultural understanding

A quarter of a century ago, Dunn<sup>29</sup> observed that the interactions between sociocultural factors and LF control had largely been ignored, and that few attempts to bridge the gap between biomedical knowledge and indigenous perceptions of disease had been attempted. While there has been some growth of the literature in this area, insights and understandings remain limited. Of the 80 countries known to be endemic for LF, sociocultural information is available for only 11 (Brazil, French Polynesia, Ghana, India, Kenya, Malaysia, Nigeria, Papua New Guinea, the Philippines, Thailand and the United Republic of Tanzania).

Disease control programmes in developing countries often fail to fully meet their objectives because the strategies pursued are inappropriate for the community or challenge local perceptions of aetiology, prevention and control. Identification of appropriate and sustainable filariasis treatment and prevention strategies requires a broad understanding of local disease perceptions, including causes, consequences and means of prevention. Since disease perceptions vary geographically, in-depth studies of the social, cultural and economic aspects of disease will need to be context-specific. The involvement of the community should be extended beyond a cursory consultation at the beginning of the process.<sup>42</sup> Community involvement and awareness must underpin and direct the ongoing evolution of filariasis elimination programmes.

Sociocultural research methodologies have been employed by researchers in Africa,<sup>20,35</sup> the Caribbean<sup>24</sup> and India.<sup>28</sup> The use of focus groups, key informants and participant appraisal techniques yield quantitative and qualitative data that improve the understanding of local ways of accounting for, explaining and treating the disease. Equally, they can help to identify those in the community at risk of failing to comply with the treatment regimes, including migrant workers. Social science research illuminates political power structures and stakeholder groups within communities, enabling programmes to include all social groups. It also allows delineation of health service, drug and community factors that influence compliance.<sup>43</sup>

The collection of robust sociocultural data should inform the planning

and management of an LF elimination programme. First, an understanding of local descriptions and interpretations of the disease is essential for informing and guiding the development of programmes' education and communication components. Equally, without the support of local leaders and their participation as proponents and advocates, the achievement of sufficiently high levels of coverage with drug combinations to interrupt disease transmission will be elusive. Secondly, as the long-term morbidity associated with pre-existing disease will continue to persist after transmission is interrupted, sensitive approaches developed in partnership with the community are required to generate the necessary impetus for effectively tackling the burden of chronic disability post-elimination.

## Conclusions

Efforts to interrupt transmission and eliminate LF as a public health problem will certainly depend on effective mass chemotherapy campaigns and other public health strategies, including vector control where appropriate. However, to increase the success of elimination strategies, the sociocultural understandings of affected community groups are pivotal in achieving sustainability, local participation and ownership. Early evidence suggests that long-term efforts to eliminate the disease may fall short of elimination in areas where community acquiescence has been replaced by distrust, engendered by misguided communication and vertical programme delivery, or a shift in local power structures. Strategies responsive to community

sociocultural understandings will have key roles in reversing this trend and in addressing the disability burden that is currently only superficially understood in affected communities. If disability is detected early and correctly managed, the negative economic and psychosocial consequences may be averted.

To sustain interruption of the LF transmission cycle and prevent this disease's negative impacts on future generations, sociocultural analysis must be brought into the mainstream of LF elimination efforts. By ensuring that sociocultural perceptions are critical in developing programme strategies and policies, we stand a much greater chance of eliminating LF. ■

**Competing interests:** None declared.

## Résumé

### Comprendre l'impact de la filariose lymphatique au niveau communautaire par une analyse de la littérature dans le domaine socioculturel

La filariose lymphatique (FL) est endémique dans environ 80 pays tropicaux et subtropicaux. Quelque 120 millions de personnes sont infestées par le parasite responsable de cette maladie et on estime à près d'un milliard le nombre de celles exposées au risque d'infestation. A ce jour, l'axe d'intervention principal du programme d'élimination de la FL consistait à interrompre la transmission de la maladie par des séries sur quatre à six ans de campagnes annuelles de traitement des communautés par l'association diéthylcarbamazine/albendazole ou l'association albendazole/ivermectine. Tout en enregistrant des succès substantiels partout où ils avaient réussi à appliquer cette stratégie, les responsables du programme ont néanmoins compris que celle-ci n'apporterait pas seule une solution durable dans tous les contextes. La littérature relativement abondante sur la FL comprend principalement des travaux de recherche sur cette maladie et des évaluations

quantitatives sur le terrain de son impact (notamment des études sur la prévalence locale des infestations humaine et vectorielle). A mesure que le programme d'élimination mondiale de la filariose lymphatique se développe, les responsables reconnaissent de plus en plus l'absence de compréhension des aspects socioculturels de la maladie comme une lacune rédhibitoire pour la mise au point de programmes adaptés et répondant aux perceptions et aux besoins locaux. Le présent article évalue l'état actuel des connaissances sur les éléments socioculturels associés à la LF. Sa conclusion est que la compréhension actuelle des facteurs socioculturels liés à la présence et au traitement de cette maladie est insuffisante et qu'il faut recourir à des méthodes appropriées, du domaine des sciences sociales, pour combler cette lacune et pour s'assurer de la participation des communautés à la délivrance des programmes d'élimination de la LF et au maintien de leur succès.

## Resumen

### Comprender el impacto comunitario de la filiaris linfática: revisión de la bibliografía sociocultural

La filiaris linfática es endémica en aproximadamente 80 países tropicales y subtropicales. Alrededor de 120 millones de personas están infectadas por el parásito que la causa, y se estima que unos mil millones están expuestas al riesgo de infección. El principal objetivo del programa de eliminación de la filiaris linfática hasta la fecha ha sido la interrupción de la transmisión mediante campañas de tratamiento anuales a escala comunitaria con dietilcarbamazina y albendazol, o bien albendazol e ivermectina, durante un periodo de cuatro a seis años. Aunque se han registrado grandes progresos en todos los lugares donde se ha conseguido aplicar eficazmente esa estrategia, paralelamente a las mejoras iniciales ha habido que reconocer que por sí sola la estrategia no garantizará la continuidad de los resultados en todos los entornos. La bibliografía sobre la filiaris linfática, bastante extensa, está dominada por las investigaciones de laboratorio y la medición cuantitativa sobre el

terreno del impacto de la enfermedad, en particular por estudios sobre la prevalencia local en poblaciones humanas y de vectores infectadas por el parásito. Conforme se amplía el programa mundial de eliminación, la ausencia de datos sobre el contexto sociocultural se está revelando como un obstáculo fundamental para articular unos programas apropiados y con capacidad de respuesta a las necesidades y las ideas locales. En este artículo se evalúa el estado actual de los conocimientos sobre el entorno sociocultural de la filiaris linfática. Se llega a la conclusión de que por el momento no se conocen suficientemente los factores socioculturales asociados a la presencia y el tratamiento de la enfermedad, y de que deberían utilizarse los métodos sociológicos oportunos para corregir esa deficiencia y asegurar la colaboración de la comunidad en la ejecución de los programas de eliminación de la filiaris linfática y el mantenimiento del éxito con ellos logrado.

## ملخص

## فهم تأثير داء الفيلاريات اللمفي على المجتمع: مراجعة للأدبيات الاجتماعية والثقافية

يتوطن داء الفيلاريات اللمفي في ما يقرب من ثمانين بلداً من البلدان المدارية ودون المدارية، ويقدر عدد المصابين به بمئة وعشرين مليوناً، فيما يزيد عدد المعرضين لخطر العدوى به عن البليون. وقد تركزت بؤرة الاهتمام الرئيسي لبرنامج التخلص من داء الفيلاريات اللمفي على قطع السراية بتنفيذ الحملات السنوية للمعالجة الشاملة للمجتمع بالديميتيل كاربامازين والألبندازول، أو الإيفيرميكتين والألبندازول، لمدة تتراوح بين أربع وست سنوات. ورغم أن تقدماً ملحوظاً قد تحقق في المناطق التي طُبِّقَتْ فيها هذه الاستراتيجية بنجاح، فإن المكاسب الأولية أثبتت أن هذه الاستراتيجية لن تكون لوحدها الحل الدائم في جميع المواقع، ويغلب على الأدبيات المنشورة حول داء الفيلاريات اللمفي البحوث المخبرية والقياسات الميدانية الكمية لتأثير داء

الفيلاريات اللمفي، ولاسيما دراسات الانتشار المحلي للمصابين بالعدوى من البشر ومن العوامل الناقلة للمرض. ومع التوسع في البرنامج العالمي لاستئصال المرض، أصبح غياب الفهم الاجتماعي والثقافي هو العيب الرئيسي الذي يحول دون ضمان ملاءمة البرامج لتلبية الاحتياجات والاستجابة لها وفهمها. وتقدم هذه الورقة تقييماً للوضع الحالي للفهم الاجتماعي والثقافي لداء الفيلاريات اللمفي، ثم تُخَلِّصُ إلى أنه يوجد في الوقت الحاضر فهم قاصر للأوضاع الاجتماعية والثقافية المصاحبة لوجود المرض ولعاجته، كما يوجد طرق ملائمة في العلوم الاجتماعية ينبغي استخدامها للتصدي لحالات القصور هذه، ولضمان الشراكة المجتمعية في تنفيذ وضمان استمرار النجاح لبرامج التخلص من داء الفيلاريات اللمفي.

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