

Review Title

The Experience of Living with Co-Morbidities of Chronic Lymphatic Filariasis among Patients 15 Years and Older in Developing Countries: A Systematic Review

Reviewers

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Background

Lymphatic filariasis (LF) is a painful and profoundly disfiguring disease that is usually acquired in childhood and manifests in adulthood, resulting in temporary or permanent disability. It has a major and far reaching social and economic impact on developing countries^{1,2}. LF accounts for 5 million Disability Adjusted Life Years (DALYs) lost annually and it ranks third to Malaria and Tuberculosis among disease conditions that the World Health Organization (WHO) Special Programme for Research and Training in Tropical Diseases (TDR) focuses on. India and countries in Africa account for 85-90% of the estimated disease burden calculated in DALYs annually³. LF is caused by threadlike parasites, such as: *Wuchereria Bancrofti* (in 95% of cases) and *Brugia malayi* or more rarely, *Brugia timori*. *Culex* mosquitoes transmit *W. Bancrofti* in India or *Anopheles* in Africa. *Brugia malayi* or *timori* are transmitted by *Mansonia* mosquitoes¹. The Executive Board of the WHO at the 50th World Health Assembly identified the human suffering, social stigma and costs associated with LF morbidity called on member states and other affiliated agencies to work towards elimination of the disease⁴.

The term chronic manifestations of LF refers to the clinical signs of Recurrent Acute Dermatolymphagioadenitis (ADLA) and Lymphoedema (Hydrocele- swollen scrotum, Elephantiasis- swollen legs, breasts or genitals) endured by sufferers of the condition⁵.

LF very rarely causes death, but is a major cause of clinical suffering, disability and handicap. More than 1.3 billion people in 83 countries and territories (approximately 18% of the world's population) live in areas where the risk of getting the infection is very high. Approximately a third of those at risk live in India, another third in Africa and the rest in Asia, the Pacific and the Americas. Bangladesh, the Democratic Republic of Congo, Indonesia, Madagascar, Nigeria and the Philippines are among the most highly endemic areas¹.

An estimated 120 million people mainly in tropical and sub-tropical areas of the world are infected. Almost 25 million men suffer from genital disease (mostly hydrocele, chylocele and swellings of the scrotum and penis), about 15 million, mainly women have lymphoedema or elephantiasis of the leg and

acute and recurrent secondary bacterial infections - ADLA. The vast majorities of infected people are asymptomatic, but have sub-clinical lymphatic damage and up to 40% have renal involvement with proteinuria and haematuria ¹. Scientific evidence suggests that lymphatic filariasis is not common among people below the age of 15 years. However in endemic regions, any individual with any form of lymphoedema, hydrocele or elephantiasis needs to be seen as a case of lymphatic filariasis ⁵.

The elimination strategy for lymphatic filariasis consists of two components:

- a. The first is the implementation of primary preventive measures of Mass Drug Administration (MDA) to reduce microfilariae prevalence levels with the aim of interrupting filarial transmission in endemic regions. This will ultimately lead to preventing the occurrence of new infections and new disease; and
- b. The second is to implement secondary and tertiary preventive measures aimed at preventing and managing acute and chronic disability and suffering in individuals already affected by lymphatic filariasis. This is to enable those suffering from the condition to have a better quality of life and be able to live fulfilling social and economic lives ^{1,5}.

This review will focus on the state of health and experiences of persons living with the chronic manifestations of LF as well as on the second component of the Global Elimination Strategy for LF. Steps have been taken by the WHO to attain this goal. At a meeting of experts held in Geneva in 2006, there was a consensus to provide strategies and measures that would be practically implementable in the field ⁵. Approaches to the management of manifestations of CLF have been developed and tried in populations with the condition. Treatment of conditions like ADLA and Lymphoedema has been documented. These approaches to managing persons with the disease are mainly based on hygienic maintenance of swollen limbs and genitals as well as seeking urgent care for expert advice in instances of acute infections of swollen extremities. Studies have shown that persons who follow the treatment modules have had significant improvements in their living conditions and are able to integrate better into society.

People living with chronic clinical manifestations of LF have certain perceptions, beliefs experiences as well as problems that inhibit the adequate management of the condition ⁶⁻⁹. These factors need to be addressed to enhance the administration of quality care for them and ultimately lead to improved health and social life.

Review Objectives

The objective of this systematic review is to understand the experiences of persons 15 years and older living with Chronic Lymphatic Filariasis (CLF) in developing countries.

The specific review questions are:

1. What are the experiences of persons living with CLF?
2. What are the experiences of persons with CLF about strategies used to prevent/ treat the condition?
3. What is the influence of CLF on social relationships of persons affected?

Inclusion criteria

a. Types of Participants

The review will consider publications that focus on developing countries and specifically include people of 15 years and older with manifestations of CLF.

b. Phenomena of Interest

The review will focus on studies that investigate the experience of living with manifestations of CLF. The review will also focus on studies that address the experiences and subjective opinions of persons that have employed various strategies of prevention/ treatment of the condition. The review will also consider studies that address the social relationships of persons living with CLF.

c. Types of Studies

The review will consider studies that are based on qualitative study designs, including but not limited to: phenomenology, grounded theory, action research, narrative studies, descriptive studies, ethnographies, cultural studies, behavioral studies, case studies and feminist research. Such qualitative studies may include various research methods such as focus group discussions, narrative descriptions, observations and interviews. In the absence of research studies, other texts such as opinions/ expert opinions/ commentary papers and reports will be considered.

Search Strategy

The search strategy aims at finding both published and unpublished (or grey literature) studies for the period 1980-2007. A three-step search strategy will be utilized in each component of this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. The databases and search engines to be searched will include:

1. PubMed
2. MEDLINE
3. EMBASE
4. CINAHL
5. HINARI
6. PSYCINFO
7. GOOGLE SCHOLAR
8. TRIP (Turning Research into Practice)
9. Natural Medicines Comprehensive Database
10. Sociological Abstracts
11. BioMed Central
12. SCOPUS
13. Current Contents
14. QuEST (Qualitative Evidence Synthesis Texts)
15. Psychology and Behavioral Sciences Collection
16. PsycARTICLES
17. Scirus.com
18. LILACS (Latin American and Caribbean Health Sciences Literature)
18. The Qualitative Report (via JBI website)
19. Qualitative Inquiry (<http://qix.sagepub.com/>)
20. ACP online
21. Bandolier – Evidence Based Health Care
22. The American Society of Tropical Medicine and Hygiene (<http://www.ajtmh.org/misc/terms.shtml>)
23. Journal publishers' websites:

Blackwell-Synergy
Cambridge Journals Online
Kluwer Online
Oxford Journals Online
SAGE Journals Online
Elsevier Science
SpringerLink
Taylor & Francis Online Journals
Wiley Interscience
CrossRef search - searches full text from several publishers.

The search for unpublished studies or grey literature will include contacting experts in the field on information not yet published, and the following databases:

1. Digital Dissertations
2. WHOLIS (World Health Organization Library Database)
3. BVS Virtual Health Library
4. Index of Theses
5. Grey Literature Report
6. Grey Literature Bulletin
7. NLM Gateway
8. Clinical Medicine Netprints Collection
9. Grey Source: A Selection of Web-Based Resources in Grey Literature
10. Networked Digital Library of Theses and Dissertations
11. PsycEXTRA
12. Popline
13. PAHO (Pan American Health Organization)
14. AHRQ (Agency of Healthcare Research and Quality)
15. DIVA Academic Archive Online
16. Althealth Watch

Initial keywords to be used include combinations of the following: lymphatic filariasis, lymphoedema, elephantiasis, hydrocele, dermatolymphangioadenitis, ADLA, management, developing countries, social relationships, societal attitudes, social attitudes, stigma, medications, microfilaria, macrofilaria, wuchereria bancrofti, brugia malayi, brugia timori, culex spp., culex mosquito, anopheles spp., antibiotics, physiotherapy, surgery.

Assessment of Methodological Quality

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I).*

*Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data Collection

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II).* * *The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

*Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

**Opinion and commentary-based texts will require NOTARI appraisal and synthesis tools.

Data Synthesis

Qualitative research findings will, where possible be pooled using the Qualitative Assessment and Review Instrument (JBI-QARI). This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rates according to their quality, and categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories are then subjected to a metasynthesis in order to produce a single

comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Conflicts of Interest

None known so far

References

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4. The Resolution of the Executive Board of the World Health Organization, Fiftieth World Assembly, WHA 50.29, Geneva, 1997.
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6. Person B., Bartholomew L. K., Addiss D., van den Borne B. Disrupted Social Connectedness among Dominican Women with Chronic Filarial Lymphoedema. *Patient Education and Counseling*. 2007; 63(3): 279-286.
7. Kron M., Walker E., Hernandez L., Torres E., Libranda-Ramirez B. Lymphatic Filariasis in the Philippines. *Parasitology Today*. 2000; 16(8): 329-333.
8. Wynd S., Melrose W.D., Durrheim D. N., Carron J., Gyapong M. Understanding the Community Impact of Lymphatic Filariasis: A Review of Sociocultural Literature. *Bulletin of the World Health Organization*. 2007; 85(6): 421-500.
9. Babu B.V., Hazra R.K., Chhotray G. P., Satyanarayana K. Knowledge and Beliefs of Elephantiasis and Hydrocele of Lymphatic Filariasis and some Sociodemographic Determinants in an Endemic Community of Eastern India. *Journal of the Institute of Public Health*. 2004; 118: 121-127.