

# THE THIRD NATIONAL SEMINAR ON EVIDENCE-BASED AND INTEGRATED MEDICINE FOR LYMPHATIC FILARIASIS, OTHER CHRONIC DERMATOSES AND HIV/AIDS



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## Editorial

When I first considered morbidity control for patients with swollen limbs caused by lymphatic filariasis, I was aware of the fierce controversies at international meetings as to whether the conservative therapies practiced in Europe should replace the surgical therapies currently practiced in India. In the UK, surgeons were not happy with the low level of patient satisfaction on long-term follow-up of surgical debulking. Thus, the favourable long-term results on follow-up of large numbers of patients in India was questioned.

Countries affected by lymphatic filariasis were mostly afflicted by a level of poverty that made surgery unaffordable, even if provided with generous discounts, and post-surgery care was unaffordable.

When reviewing whether it might be possible to provide low-cost solutions at the village level, Babar Vaqas and I outlined all the locally available low-cost resources available (Vaqas and Ryan, 2003) and, as a visitor to India, it seemed that that country might find such care was well provided through the Indian System of Medicine.

Dr SR Narahari of The Institute of Applied Dermatology (IAD), Kasargod, Kerala, thought so too and set out to create a team in which biomedicine concepts were integrated with Ayurvedic medicine in particular.

I was surprised by how well the team at the IAD managed to put these ideas into practice. I should not have underestimated the wisdom of India. First, we had the efficacy of Ayurveda after a process of selection from diverse sources of ancient texts. This we have already described (Narahari et al, 2007). Now, in this supplement, we describe the advantages of working with the Indian patient with their close-knit families and village communities. Not only are they more comfortable with the demands of yoga and herbal preparations, but they have greater support from families and their communities than we experience in Europe.

This supplement, consisting of a collection of presentations given at a workshop in Kasaragod in February, 2008, provides an insight into how Indian culture absorbs some of the concepts applied to disability from the West and puts them into practice.

Terence Ryan, Emeritus Professor of Dermatology, Oxford  
March, 2009

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# MORBIDITY CONTROL BY PATIENT EMPOWERMENT

SR Narahari, KS Bose, GM Aggithaya, KS Prasanna

The third national seminar on Evidence-based and Integrated Medicine for Lymphatic Filariasis, other Chronic Dermatoses and HIV/AIDS held on 5–7th February, 2008 was jointly organised by the Institute of Applied Dermatology (IAD), Kerala and the International Lymphoedema Framework (ILF), London. The seminar covered self-care, low-cost and home-based treatment for lymphoedema. The strategies for the implementation of patient participation in treatment lead by patient support groups were discussed by experts in the field. Community medicine experts, working for the management of chronic diseases such as HIV/AIDS described how they managed stigmatic diseases at community level in India. An Ayurvedic basis for integrative treatments was also discussed, as well as health-related quality of life as an outcome measure. Forty-three patients demonstrated the programme of self-care integrative treatment that has been developed by IAD. The meeting was supported by the Indian and Kerala governments.

## Key words

Ayurveda  
Integrated medicine  
Patient empowerment  
Traditional medicine

Even as the Global Alliance for the Elimination of Lymphatic Filariasis (GAELF) was planning the discussion of the treatments available for lymphatic filariasis (LF) in a two-hour morbidity control session in its April 2008 meeting to be held in Tanzania, two groups involved in the development of treatments for lymphoedema in the East and West, the Institute of Applied Dermatology (IAD), Kerala, and the International Lymphoedema Framework (ILF), London, came together to discuss the future strategies for morbidity management of lymphoedema in high prevalent nations. This (3rd) national seminar on Evidence-based and Integrated Medicine

for Lymphatic Filariasis, other Chronic Dermatoses and HIV/AIDS on 5–7th February, 2008 was jointly organised in Kasaragod, Kerala, South India. LF is a global disease caused by a parasite transmitted by mosquitoes. The World Health Organization (WHO) classified LF (elephantiasis) as a 'neglected disease of the poor', because there is little research into this tropical disease and both industry and governments have ignored causation for too long. One-third of the world's affected persons live

**Most patients, many of whom were once their family's breadwinners, live in villages and are disabled by their swollen legs and suffer repeated, infection-induced feverish episodes.**

in India. Elephantiasis causes appalling disfigurement with estimated losses of US \$1 billion annually to the Indian rural economy (Ramaiah et al, 2000). Most patients, many of whom were once their family's breadwinners, live in villages and are disabled by their swollen legs and suffer repeated, infection-induced feverish episodes.

GAELF is supporting its elimination programme through mass drug administration (MDA) to over a billion

populations in 80 countries. Over 473 million Indians who are at risk of infection receive therapy once a year in November for at least five consecutive years. India has long used diethylcarbamazine (DEC) and favours mono drug therapy. These drugs kill parasites circulating in the blood and break disease transmission. However, the drugs have little effect on swollen limbs. Treatment of LF has not yet been activated as a major part of any global programme. Although an estimated 23 million people are disabled due to elephantiasis, the Indian Government does not currently have any special programme to address their disability. Since disease affects the poor, private health care has little interest in managing these patients. Therefore, a gap exists in terms of treating LF disability. The ILF identifies other causes of lymphoedema and emphasises that it would be wrong to focus only on a single cause, such as filariasis, which, even though affecting huge numbers, may not account for half the world's lymphoedema patients. As recently reported in China which once had 30 million cases of elephantiasis, elimination of filariasis has been followed by about 60,000 new cases of lymphoedema each year due to other causes such as cancer and its treatment (Liu, 2004).

Having demonstrated to peers the efficacy and scientific basis of integrated self-care treatment in the two previous

SR Narahari, Director; KS Bose, Principal, administration and communications; GM Aggithaya, Chief Consultant Ayurveda; K Prasanna, Consultant Dermatologist, the Institute of Applied Dermatology, Kerala, Kasaragod, India



Presentations focusing on creating patient support peer group cooperatives (PSPG) for LF followed. Mr S Praveen, South India Coordinator Credibility Alliance, presented how his organisation was evolving norms to identify credible non-governmental organisations (NGOs) in India and methods to form credible alliances with PSPG. Mr UG Upadhya, First hospital executive of Jindal Hospital, Bangalore, presented his experiences of creating new centres of treatments: 'From zero to one: How to create and involve the ayurveda set ups at grass root level?'

The centerpiece of the seminar was a display by 43 patients, as representatives of 393 patients who had received the integrated, self-care and home-based treatment of IAD for lymphoedema. Patients of all stages of primary and secondary lymphoedema, who had been performing this self-care treatment from 45 days to two years, participated in this four-hour session. Each patient's baseline and follow-up photos and clinical data were displayed on a screen. Peers and delegates examined the patients and interacted with them to learn their experience of taking integrated treatment. Eight patients narrated their experience and how they felt before and after the treatment. Others demonstrated all stages of the self-care integrated treatment protocol (Addiss and Buettner, 2004; Narahari, 2007); namely, water wash using acidic soap, phanta soaking, drying, pre-Indian manual lymphatic drainage Yoga exercises to drain the central lymphatic, inguinal and popliteal nodal lymph drainage, Indian manual lymphatic drainage (Ayurvedic skin care also called *udwarthana*), compression using long-stretch compression bandages with special emphasis on de-kinking of lymphatic trunks, and post-Indian manual lymphatic drainage yoga exercises.

Physiotherapist, Gerben Schrale from The Netherlands, gave a two-hour demonstration on how to treat lymphoedema using European techniques. He emphasised that lower limb lymphoedema care in India was being implemented against a difficult clinical background and that European healthcare providers could learn from the IAD experience.

On the third day, Dr KH Prakash, Deputy Director of Karnataka Health Promotion Trust, narrated ways of communicating to NGOs/community-based organisations [CBOs]/filariasis patients and the public to achieve morbidity reduction of India's 25 million LF population, spread over 20 states, by patient empowerment through PSPG. Dr Showkath Ali, Joint Director and Head, Regional Centre National Institute of Communicable Diseases, Kozhikode, stressed the importance of translating education into local languages, emphasising how the frequency of recurrent attacks of filarial fever had been reduced in patients attending their centre because they had provided training for soap and water wash, mild exercises and information, education and communication (IEC) materials in local languages.

One session was entirely devoted to the assessment of health-related quality of life (HRQoL) to evaluate the impact of morbidity management and disability prevention activities. Dr Philip Morgan, previously project director, ILF, London gave a review of western quality of life (QoL) literature in lymphoedema. Dr Harischandkumar, VCRC, WHO Collaborating Centre for Research and Training in Lymphatic Filariasis presented their method of assessing the health status of patients with different clinical manifestations of LF using mobility, self-care, usual activities, pain, anxiety/depression, cognition and social participation domains, and scoring for no problem to extremely severe problem. Dr Krishna Kumari's paper was on determination of disability weight for different clinical manifestations of LF using DALY scores at VCRC. One consequence of this session will be a survey of QoL employing an extensive collaboration to define therapeutic manoeuvres that have the most influence.

The seminar also discussed results of newer approaches in integrated treatment for poor responders that have been suggested by experts (Narahari et al, 2007), physiotherapeutic manoeuvres to improve muscular strength of the contralateral, unaffected leg and trunk in lymphatic filariasis, bioethics related

## Key points

- ▶▶ The seminar was jointly organised by the Institute of Applied Dermatology (IAD), Kerala and the International Lymphoedema Framework (ILF), London and supported by the central and provincial Governments of India.
- ▶▶ The seminar focused on implementation of morbidity reduction of lymphoedema using patient support peer group cooperatives.
- ▶▶ Experts discussed various related topics such as Ayurvedic treatments and evidence available for treatment.
- ▶▶ Patients demonstrated self-care and home-based treatments.

to community participation, and other Indian local health traditions in the management of lymphoedema. JL

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# USING HRQOL TO ASSESS THE IMPACT OF MORBIDITY MANAGEMENT

K Krishnamoorthy, A Krishna Kumari, KT Harichandrakumar, LK Das

## Abstract

**Background:** Health-related quality of life (HRQoL), which refers to patients' perceptions of the effect of disease on their physical, psychological and social function and well-being is appropriate in evaluating and comparing healthcare interventions. Lymphatic filariasis (LF) has been targeted for elimination which includes morbidity management to prevent disability and improve patients' quality of life. **Aims:** To assess the impact of morbidity management using a disease-specific instrument. **Methods:** The steps involved in the development of the instrument included item generation (enlisting of items), item reduction (shortlisting of items), construction of questionnaire, validation of questionnaire and pre-testing the questionnaire. **Results:** 137 items relevant to health domains affected by LF were shortlisted from 200, based on clarity, frequency and relevance. 36 items with higher clinical impact score (CIS), grouped under different hypothesised domains, were included in the final questionnaire. Maximum CIS was obtained for psychological related difficulties followed by physical difficulties. An instrument was constructed with appropriate questions for each item identified and specified response options using a five-point scale, ranging from the worst (1) to the best (5) possible function. **Conclusions:** A disease-specific instrument to assess the HRQoL of a patient with LF was developed. This tool can evaluate the impact of morbidity management, an important intervention to achieve the goal of elimination of lymphatic filariasis.

## Key words

Elimination of lymphatic filariasis  
Morbidity management  
Health-related quality of life

Traditionally, outcomes in medicine and health care have largely been determined by objective medical evaluation. There is an increasing recognition that what matters most to patients is how well they are able to function in their day-to-day life (Hays et al, 1994), and self-reported health status is receiving increasing attention in epidemiology and outcome research (Anderson et al, 1999). Measures of the impact of chronic diseases on patients' lives

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are required for clinical, audit and political reasons to argue for more resources (Finlay 1997, 1996; David et al, 2005). As a result, emphasis has shifted towards including evaluations of medical/health-related outcomes from the patient's perspective. The measurement of health-related

## HRQoL can supplement clinical information on patients' health status, providing additional information beyond that offered by traditional medical and clinical measures.

quality of life (HRQoL) is increasingly becoming part of the overall assessment of a patient's health, both in the clinical and research setting, as it provides a more complete picture of the health of the patient.

Traditional physiological or biological measures of health status provide information about the lowest levels of health, but reveal little about other

important aspects of an individual's health or a community's level of health, including dysfunction and disability associated with diseases, injuries and other health problems. Health-related quality of life, a multi-dimensional construct, measures the individual's perceptions of the impact of disease and treatment on their physical, psychological and social function and well being (Badia et al, 2005; Teewee et al, 1998), and is crucial in the evaluation of healthcare interventions (Feeny et al, 2004). It can supplement clinical information on patients' health status, providing additional information beyond that offered by traditional medical and clinical measures. By offering a profile of the current state of an individual who is experiencing a particular illness or chronic disease, HRQoL measures are potentially of use to clinicians, researchers, administrators and policymakers. It is now widely accepted and has become an important outcome measure in clinical trials and health service research (Testa and Simonson, 1996):

The Global Programme to Eliminate Lymphatic Filariasis (GPELF) was

established in early 2000 following the World Health Assembly Resolution 50.29 (WHA) in 1997. The GPELF has two components. Firstly, to interrupt the transmission of infection through mass drug administration (MDA) with diethylcarbamazine (DEC) or co-administration with albendazole by reducing filarial infection load. Secondly, to reduce LF-related disability in those already affected by chronic manifestations of the disease through a morbidity management programme (Gyapong et al, 2005). The morbidity management programme includes basic limb hygiene, which can prevent secondary infections causing acute episodes (adenolymphangitis) among lymphoedema patients, and surgical corrections for hydrocele cases. The objective of morbidity management is to enable those who have already been affected to have a better quality of life and be able to participate fully, both socially and economically (World Health Organization [WHO], 2006a).

LF has a wide clinical spectrum (Pani et al, 1995) and disability is more pronounced in the advanced stages of lymphoedema and hydrocele. Since the advanced stages of lymphoedema are irreversible, a morbidity management programme can lessen the disabilities due to secondary infections and thereby improve quality of life. Persons with chronic diseases may be more concerned with function and well-being, rather than the physiologic measures that healthcare providers find useful (Guyatt et al, 1993). HRQoL is of particular concern to those with chronic disease for which a cure is unlikely (Smith et al, 1999). It can be considered an important primary outcome in the assessment of the impact of the morbidity management programme (Krishna Kumari et al, 2007). Assessment of HRQoL provides a way of understanding better the effect of LF on the overall functioning and well-being of patients. Such an understanding promises to influence the quality of care provided to patients with LF.

Two basic types of HRQoL measurements are available: generic and disease-specific instruments.

Generic instruments assess the general aspect of HRQoL applicable to any disease or health condition, but lack the sensitivity to detect any changes after intervention. Disease-specific instruments mainly assess the particular concerns and conditions related to that particular disease or health state (Engel et al, 2006), and are more sensitive to detect the changes between the pre- and post-intervention period. Thus, the latter are more appropriate to assess the impact of the morbidity management programme.

The aim of this study was to develop a disease-specific HRQoL instrument that includes items commonly found in patients with LF, as a tool to assess the impact of the morbidity management programme.

### Methods

The following steps were undertaken to develop a disease-specific HRQoL instrument for lymphatic filariasis (LF-QoL).

#### Item generation

The purpose of this phase was to identify the problems and difficulties (items) that might be potentially affecting the daily life of patients with LF. These items were identified using four standard methods. First, we conducted a comprehensive review of the LF literature. Second, we sought the opinions of medical experts, the collective experience of the study investigators and clinic staff. Third, we used focus group discussions with patients with LF and their relatives to discuss the impact of LF on their daily lives. Fourth, we conducted semi-structured interviews with the patients. These interviews included open-ended questions about all possible aspects of a patient's life that might be adversely affected. From content analysis based on all of these approaches, a list of items likely to be important to patients with LF were identified. Item generation was discontinued when no new items were identified. From the preliminary set of items generated, the items were shortlisted after redundant items with similar meaning and those causing confusion were eliminated.

#### Item reduction/selection

The purpose of this phase was to determine which of the shortlisted items were most commonly experienced and were most important to patients with LF. The items were reduced using the clinical impact method (Juniper et al, 1997). This method is consistent with the definition that quality of life 'represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient' (Schipper et al, 1990). Clinical impact testing asks the patients to identify those items that they have experienced as a result of their illness.

A clinical impact questionnaire was prepared and administered to patients with LF to identify how frequently the event happened, and how important it was to them. For each item, the clinical impact method asks two questions: (1) Was it a problem for them? (yes/no), and (2), if it was a problem, how important was it to their quality of life? (five-point scale ranging from 'not very important' [zero] to 'extremely important' [four]). For each item the frequency that respondents answered 'yes, it was a problem' was recorded (frequency).

Next, the mean importance score for each item was determined (importance), and finally the clinical impact score (CIS) was calculated as the product of these two numbers (frequency x importance). The items with lowest CIS were considered for removal and those with higher CIS (occurring more frequently and considered more important) were considered for the development of the LF-QoL. Discussion with experts indicated which items could be removed without losing important information from a clinical assessment perspective. The selected items were grouped into hypothesised domains. A domain refers to the area of behaviour or experience being measured.

#### Questionnaire construction

We constructed appropriate questions for each item identified for LF-QoL. A 5-point response option was given

across each questions to assess the magnitude of the problem. The response option ranged from worst (1) to best (5). The response options for the 'bother' questions were defined as: (1) extremely bothered; (2) quite bothered; (3) somewhat bothered; (4) hardly bothered and (5) not bothered. The response options for the 'how often' questions were defined as: (1) all of the time; (2) most of the time; (3) some of the time; (4) hardly any of the time and (5) none of the time. Along with these types of questions, a general health rating question was also included: 'In general, how is your health?'. The response options were (1) poor, (2) fair, (3) good, (4) very good, (5) excellent.

## Results

### Item generation

A pool of items was generated by the literature review, expert opinion, focus group discussions and in depth interviews with patients with LF. The strategy was to first carry out a literature search to identify relevant papers describing the impact of LF in HRQoL and the items were recorded. Secondly, five medical experts well conversant in the treatment and research of LF were asked to identify those items and domains of LF they believed would cause problems in patients' daily lives. Subsequently, three focus group discussions with patients and their family members were held in their domestic settings to identify their problems due to LF. Each group consisted of ten participants. Finally, 10 in-depth, semi-structured interviews with patients with LF were conducted. Item generation was stopped when no new items were identified in the last three interviews. From these transcripts, a series of 200 items were obtained and short-listed to 133 which are relevant to the disease and the HRQoL measure.

### Item reduction

In view of making the instrument brief, simple and to avoid cognitive problems and stress to the respondents, the 133 items were further shortlisted by eliminating items with jargon, items considered ambiguous, complicated,

double-barrelled, and also those with too long or negatively worded questions. This left 41 items. The 41 items were sent to a group of experts in the treatment of filariasis to check whether any relevant items had been included (excluded) in the reduction process. The 41 items were carefully assessed and approved by the experts for further procedure.

Item reduction was carried out through the clinical impact scores. The clinical impact questionnaire of 41 items was administered to 46 patients with chronic manifestations of LF (23 males, 23 females). The average age of patients was 51 years and was not significantly different ( $P>0.05$ ) between the genders. Of these 46 patients, 12 had hydrocele and others had lymphoedema. The CIS was calculated for each item as the product of frequency and importance, and the items with higher CIS were selected for inclusion in the LF-QoL. The mean CIS for some of the selected items is shown in *Table 1*. The mean score was maximum in items such as interference with occupation and household activities, stress and difficulties in concentrating, followed by items of social participation, feelings of inferiority, self-consciousness and embarrassment.

## Discussion

Chronic disease can have a physical and psychological impact that affects social functioning. A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases has shown that these effects can be better understood from the perspective of patients (Beattie et al, 2006).

In public health and medicine, the concept of HRQoL refers to a person's or group's perceived physical and mental health over time. HRQoL is used by healthcare professionals to measure the effects of chronic illness and better understand how an illness interferes with a patient's day-to-day life. Similarly, public health professionals use HRQoL to measure the effects of numerous disorders, short- and long-term disabilities, and diseases in

## Key points

- ▶ As the morbidity management strategy aims at improving the quality of life of patients with irreversible clinical manifestations of lymphatic filariasis, health related quality of life (HRQoL) is considered an appropriate indicator to assess the impact of the intervention.
- ▶ An instrument (LF-QoL) to assess the HRQoL of filarial patients has been developed and pre-tested. It is the first of its kind for lymphatic filariasis.

different populations. Tracking HRQoL in different populations can identify subgroups with poor physical or mental health and can help guide policies or interventions to improve health. Assessing the impact of treatment on different aspects of a patient's HRQoL is important in clinical trials (Remor et al, 2004; Ortonne et al, 2005). Many medical interventions are designed to improve the quality, rather than extend the duration of a patient's life, and hence the measure of QoL is required to assess the benefit of such interventions (Guyatt et al, 1986). Since generic instruments are unlikely to detect small and clinically important changes, disease-specific instruments are essential to assess the benefit of therapeutic interventions (Evers et al, 2008). Such instruments are available for cancer (Spitzer et al, 1981; Preistman et al, 1976; Mor et al, 1984), heart disease (Goldman et al, 1981), asthma (Rutishauser et al, 2001), liver disease (Younossi et al, 1999), stroke (Williams et al, 1999), ophthalmopathy (Terwee et al, 1998), haemophilia (Young et al, 2004), rheumatoid arthritis (Weisman et al, 2003), etc. Evaluation of intervention programmes against LF using a disease-specific instrument has not yet been attempted and this report can be considered the first of its kind.

The morbidity management

programme associated with GPELF aims to lessen the disabilities due to secondary infections and thereby improve the QoL of patients (WHO, 2006a). HRQoL has therefore been suggested as a tool to assess the impact of the morbidity management programme (Krishna Kumari et al, 2007). The LF disease-specific HRQoL instrument was developed following standard methods described elsewhere (Badia et al, 2005; Engel et al, 2006).

The generation of items through a literature survey, as well as interaction with patients, relatives, and medical experts provided an exhaustive list. The involvement of filarial patients and discussion with medical experts in the item reduction process enhanced the content validity of the instrument. CIS quantification of items and further ranking identified the most important items for assessing the impact. GPELF has been launched in 42 of 83 countries and the morbidity management component is still in its infancy (WHO, 2006b). The disease-specific instrument developed for assessing the HRQoL in the present study can assess the impact of morbidity management, an undertaking initiated in 27 endemic countries (WHO, 2006b).

Use of WHO Disability Assessment Schedule (WHODAS) to evaluate the impact of disability prevention programmes has been recommended by the Technical Advisory Group on elimination of lymphatic filariasis (WHO, 2004). However, it is a general health state assessment measure and does not reflect the disease-specific health outcomes on which intervention measures are designed. The present LF specific HRQOL tool is designed to capture the small changes that are envisaged by the interventions, and thus is an appropriate instrument to evaluate the impact of disability prevention activities.

The final LF-QoL questionnaire consists of 37 items covering six hypothetical domains. For the development of a disease-specific HRQoL instrument for LF, appropriate

questions were prepared from each of the selected items. Incorporation of a 5-point response option across each of the questions and the definition of response options, depending on the nature of the question will facilitate the interviewer to generate data. This instrument is simple, brief and easy to administer. It can strengthen the LF elimination programme and make evidence-based decisions.

### Conclusions

The HRQoL of patients with LF is considered to be an appropriate indicator to assess the impact of morbidity management, and aims at improving the QoL of these patients. The filarial disease-specific HRQoL

instrument developed in this study has the sensitivity to detect small changes that occur during the progression of the disease, and can assess patients' functioning and well being in daily life. It can be used as a tool to evaluate the impact of the programme to eliminate lymphatic filariasis. **JL**

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**Table 1**

### Clinical impact score derived from the interviews with patients

| Item of difficulty   | Impact score | Mean impact score | %     |
|--|--------------|-------------------|-------|
| LF interfered with occupation                                    | 161          | 3.50              | 87.5  |
| LF interfered with household chores                              | 161          | 3.50              | 87.5  |
| Difficulty in concentrating                                      | 161          | 3.50              | 87.5  |
| Stress   | 161          | 3.50              | 87.5  |
| Social participation   | 154          | 3.35              |       |
| Embarrassment  | 153          | 3.33              | 83.2  |
| Self-consciousness   | 153          | 3.33              | 83.2  |
| Feelings of inferiority  | 153          | 3.33              | 83.2  |
| Difficulty in walking  | 149          | 3.24              | 81    |
| Difficulty in climbing stairs or steps                           | 149          | 3.24              | 81    |
| Difficulty in bending, kneeling or stooping                      | 149          | 3.24              | 81    |
| Difficulty in changing body positions                            | 149          | 3.24              | 81    |
| Strain in travelling long distances                              | 149          | 3.24              | 81    |
| Performing usual activities                                      | 149          | 3.24              | 81    |
| Worry  | 149          | 3.24              | 81    |
| Anxiety/fear of attacks of ADL                                   | 149          | 3.24              | 81    |
| Feeling guilty about inability to take on responsibilities fully | 149          | 3.24              | 81    |
| Depression   | 149          | 3.24              | 81    |
| Interference with happiness                                      | 148          | 3.22              | 80.4  |
| Social roles   | 148          | 3.22              | 80.4  |
| Pain   | 147          | 3.20              | 79.98 |

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# DISABILITY WEIGHT FOR DIFFERENT CLINICAL MANIFESTATIONS

A Krishna Kumari, KT Harichandrakumar, LK Das, K Krishnamoorthy

## Abstract

**Background:** Disability weight is a key component of the disability-adjusted life year (DALY), a time measure that assesses population health by combining information of years of life lost due to mortality and healthy years lost due to disability. **Aims:** To define disability weights for all the clinical manifestations of lymphatic filariasis (LF), rather than just those for lymphoedema and hydrocele, the only two health states of LF determined in the Global Burden of Disease (GBD) study (1990). **Methods:** Disability weights were determined for seven identified health states (acute to chronic) for LF by healthcare professionals and members of the general population (community) through the Health State Valuation Exercise (HSV) using a visual analogue scale. **Results:** Those in the community gave significantly ( $P < 0.05$ ) higher values for all the health states than the experts. **Conclusions:** The findings indicated that DALYs underestimate disability weights. Acute episodes of adenolymphangitis contribute maximum burden to the filarial patients. Appropriate morbidity management strategies are required for elimination of LF. This study also emphasised the need for multicentric studies at national and global level for standardisation of disability weights. **Declaration of interest:** None.

## Key words

Lymphatic filariasis  
Descriptive system  
Disability weight  
Health state valuation

Empirical information on the health status of the population is an essential element for evidence-based public health policy-making. Traditionally, mortality and its derivative, life expectancy, have been important indicators of health (Melse et al, 2000). Advances in medicine have dramatically increased life expectancy. People now live longer; but during these added years they may be affected by disease or

chronic conditions (Flanagan et al, 2005). A disease or injury may have multiple disabling effects or sequelae. For example, diabetes may result in diabetic foot ulceration, retinopathy, neuropathy, or amputation. The study on the Global Burden of Diseases (GBD, 1990) for the first time tried to estimate the total burden of disability (Christopher et al, 2002). The study provided a comprehensive and comparable assessment of mortality and loss of health due to diseases, injuries and risk factors for all regions of the world. In all, 483 disabling diseases and injuries were analysed for all regions and age groups, and for both sexes (Murray and Lopez, 2008).

The disability adjusted life year (DALY) developed by the GBD study group is widely used as a summary measure of population health, combining both years of life lost (YLL) due to mortality, and years of healthy life lost due to disability (YLD). Essential information for the estimation of DALYs includes disease specific epidemiological data and disability weights (DWs). The disability

weight is used for weighting the years lived with a specific disease by the severity of the disability associated with it (Essink-Bot et al, 2002). These weights do not represent the lived experience of any disability or health state, or imply any societal value of the person in a disability or health state, rather they quantify societal preferences for health states in relation to the societal ideal of good health (Mathers et al, 1999). They lie on a scale between 0 (indicating the health condition is equivalent to full health) and 1 (indicating the health condition is equivalent to death). The GBD study initiated in 1990, determined disability weights for different health states for assessing the burden. However, these expert-rated disability weights are available only for selected health states of a given disease, not for all health states of a disease. Disability weight is the societal preferences about the severity of different health states. In view of the practical difficulty in obtaining this information from society for all the health states, the GBD used experts on the assumption that they have a relative familiarity of

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health conditions and their outcome. However, this hypothesis has not been empirically tested. It is logical therefore to determine disability weights for all health states of a given disease through community valuation. In the case of lymphatic filariasis (LF), disability weights are available for only two chronic health states, namely lymphoedema and hydrocele, whereas the disease progression of LF shows clear stages of acute and chronic manifestations.

Lymphatic filariasis, a mosquito-borne parasitic disease, is a major contributor to disability in the developing world (Ottesen et al, 1997). Acute attacks contribute to the progression of morbidity from asymptomatic infection to lymphoedema and elephantiasis (Dreyer et al, 2002). In its most obvious manifestations, LF causes enlargement of the entire leg or arm, the genitals, vulva and breasts. The psychological and social stigma associated with these aspects of the disease is immense (World Health Organization [WHO], 1997, 1998). In the acute stage of LF, adenolymphangitis (ADL), mobility is severely affected; patients are unable to walk or move around and are confined to bed for four to seven days. The severity of morbidity rises with later stages of the disease. Mobility and self-care become difficult due to oedema, stiffness and pain in the affected organ. Strenuous physical labour and long hours of standing aggravate pain and swelling of the legs, compelling patients to completely give up their occupation or change to less strenuous work that earns nominal wages. Physical incapacity in the most productive stage of life, financial problems, dependency on others, inability to marry and lead a normal life gradually affect the mental health of the individual and lead to anxiety/depression. The gross disfigurement, stigma and shame associated with the disease makes any social life nearly impossible (WHO, 1998).

The objective of this study was to determine disability weight for seven

acute and chronic health states of LF through medical experts and in the community. The experts consisted of doctors from different hospitals and research institutes, as well as public health officials from the Directorate of Health and Family Welfare Services who had knowledge and experience about different health states of lymphatic filariasis, as well as the health states of other diseases used for relative comparison. The results of the study would provide a methodology to determine disability weight for both the acute and chronic health state of LF and enhance the data for DALY estimation due to LF.

### Materials and methods

#### Health state valuations (HSVs) through the medical experts and general population

Health state valuations (HSVs) by 15 medical experts were done through workshops. The workshops were conducted at the Vector Control Research Centre, Pondicherry. The practical session of the workshop consisted of HSV through card sorting/ranking and visual analogue scaling. In the card sorting and ranking exercise, the medical experts were given 21 health state description cards (i.e. cards containing description of the health states to be valued). The experts had to rank the different health states in order of relative severity (from best to worst). In the visual analogue scale (VAS) exercise, the valuers were given a VAS and 21 health description cards. The VAS consists of a line drawn on a page with two clearly defined end points; 100 at the top indicating the best imaginable health state, and 0 at the bottom indicating the worst imaginable health state. Valuers had to indicate their valuation of the health state by placing the health state description card on the scale according to the relative severity of each health state. Health states that are considered rather good had to be placed on the upper part of the scale, poor health states had to be placed in the middle, and worse conditions equivalent to death, to be placed at the bottom of the scale. The most frequently stated severity level was assigned to each domain.

HSVs in the community were conducted in Bahur, a village in Pondicherry, South India with a total of 155 participants. From a list of households selected at random from a village in Pondicherry, one adult member (between 15 and 60 years of age) who was available at the house was chosen for the valuation exercise. HSVs were held in their homes after obtaining informed, written consent. The purpose and method of the study was fully explained to the respondents. The HSVs were carried out using visual analogue scaling. In the valuation exercise, the valuers were given 21 cards describing different health states of diseases that were commonly found in the locality, ranging from mild to severe conditions. These health states included seven of LF covering both acute and chronic manifestations. The cards included brief information about the disease and its severity levels using the seven domains five levels instrument (7D5L) (Krishna Kumari et al, 2005; Harichandrakumar et al, 2006). For community valuations, simple graphical representations of 7D5L descriptive system were used. Using these cards, the participants had to rank the different health states in order of relative severity from best to worst by placing the health state description card on the VAS scale between 0 and 100. This was a 20cm scale with two clearly defined end-points: 100 at the top and 0 at the bottom, indicating the best and worst imaginable health state respectively. These scores were converted into disability weight using the formula  $1 - (\text{VAS value} / 100)$ .

### Selected health states of LF

#### Adenolymphangitis (ADL)

##### Lymphoedema:

- ▶▶ Grade I (L1): Lymphoedema, pitting, reversible
- ▶▶ Grade II (L2): Lymphoedema, non-pitting, irreversible, no skin change
- ▶▶ Grade III (L3): Non-pitting, irreversible, skin thickened
- ▶▶ Grade IV (L4): Same as grade III with papillomatous changes.

##### Hydrocele:

- ▶▶ Grade I (H1): Size < tennis ball
- ▶▶ Grade II (H2): Size > tennis ball.

Table 1

## Disability weight for different clinical manifestations of LF

| Health states of LF | Disability weight (mean $\pm$ SD) |                     |
|---------------------|-----------------------------------|---------------------|
|                     | Experts' valuation                | Community valuation |
| HI                  | 0.13 $\pm$ 0.09                   | 0.29 $\pm$ 0.17     |
| LI                  | 0.21 $\pm$ 0.13                   | 0.36 $\pm$ 0.16     |
| LII                 | 0.28 $\pm$ 0.13                   | 0.44 $\pm$ 0.19     |
| H2                  | 0.29 $\pm$ 0.14                   | 0.57 $\pm$ 0.19     |
| L3                  | 0.35 $\pm$ 0.14                   | 0.84 $\pm$ 0.10     |
| L4                  | 0.45 $\pm$ 0.13                   | 0.85 $\pm$ 0.11     |
| ADL                 | 0.52 $\pm$ 0.20                   | 0.74 $\pm$ 0.21     |

## Results

## Expert rated disability weight

Fifteen medical experts took part in the workshop for determining the DW for different health states of LF through HSVs, as described above. The experts gave maximum disability weight (mean) for the acute state of ADL (0.52), followed by grade IV lymphoedema (0.45); and minimum for grade I hydrocele (0.13), and grade I lymphoedema (0.21). It was also observed that the disability weight increased with progression of health states. The disability weight was found to be more in ADL than in the chronic stages of lymphoedema and hydrocele (Table 1). Among chronic cases disability weight was more for lymphoedema than hydrocele. The results proved the assumption that disability weight varies between health states of the same disease as the morbidity pattern varies.

## Community rated disability weight

A total of one hundred and fifty-five respondents participated in the study. Of these 155 respondents, 76 were male and 79 were female. The mean age of males was 29.9 and of females 26.87, the difference is not statistically significant ( $P>0.05$ ). As said, the graphical version of the 7D5L descriptive system was used for the community during the HSV exercise for determining the disability weight for filariasis and other diseases. The mean

disability weight was calculated for all the health states. The community gave the highest disability weight for grade IV lymphoedema (0.85), followed by grade III lymphoedema (0.84); and minimum for grade I hydrocele (0.29), followed by grade I lymphoedema (0.36) (Table 1). The disability weight given by the community was independent of gender ( $P>0.05$ ) in almost all the health states except for grade III lymphoedema, where the female respondents (0.87) gave more disability weight than males (0.80). It was observed that the community rated disability weight was higher for lymphoedema than hydrocele, and increased with higher grades of lymphoedema and hydrocele.

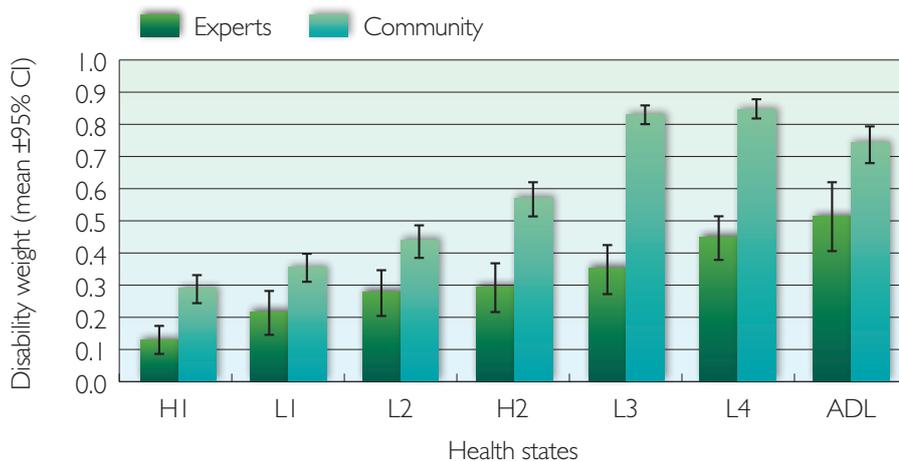
## Comparison of expert and community rated disability weight

The community gave significantly higher ( $P<0.05$ ) disability weight than the experts in all the health states of LF (Figure 1). The difference between the experts and community ratings ranged from 1.4 to 2.4 times in different health states. The order of rankings of health states based on disability weight was similar between experts and community, except for ADL. The community gave higher disability weight for grade IV lymphoedema followed by grade III lymphoedema, whereas experts gave highest disability weight to ADL followed by grade IV lymphoedema (Table 1).

## Discussion

The measurement unit disability-adjusted life years (DALYs) (Mahapatra, 2001) has been increasingly used in recent years to quantify the burden of diseases, injuries and risk factors to populations. It is grounded on cogent economic and ethical principles and can guide policies toward delivering more cost-effective and equitable health care (Murray and Acharya, 1997). Apart from conventional measures of burden of diseases, DALY has shown a different dimension of population health. Looking at the burden of disease using DALYs can reveal surprising things about a population's health. For example, mental disorders which were traditionally not regarded as major epidemiological problems when mortality indicators alone were being used, are now being ranked almost as high as cardiovascular and respiratory diseases and have surpassed all different types of cancer and human immunodeficiency virus (HIV), with the inclusion of 'disability' in the equation in calculating DALYs (Ustün et al, 1999). While there are arguments against the conceptual and technical basis for DALYs (Anand and Hanson, 1997; Paalman et al, 1998), DALY is considered to be a useful tool for setting health service priorities, allocating the available resources more effectively, and providing a comparable measure of output for early intervention (Sanchez-Valle et al, 2008).

The EuroQol questionnaire (EQ-5D), a non-disease specific instrument developed for subjectively describing and valuing health states (Brennan et al, 2004; Koning et al, 2005), represents the best method to quantify DALYs (Agency for Healthcare Research and Quality [AHRQ], 2005). EuroQol describes a health state in five domains of health (mobility, self-care, usual activity, anxiety, depression), and three severity levels (no health problems, moderate health problems, and extreme health problems). Though widely used internationally and reported to have adequate construct and convergent validity, it is highly skewed and has relatively poor sensitivity,



**Figure 1. Expert and community rated disability weight for different health states of LF.**

especially in relation to disease-based outcomes (Bowling, 2001).

To describe the health states of lymphatic filariasis as having a wide clinical spectrum, affecting major domains of health of the patients, required a sensitive instrument capable of capturing issues that are specific to lymphatic filariasis. The 7D5L descriptive system used in this study addresses this need (Krishna Kumari et al, 2005). It is a modified version of the EuroQoL and the 6D5L descriptive system used in the burden of disease study in Andhra Pradesh (Mahapatra, 2001). The 6D5L descriptive system had the domain of cognition in addition to the five domains in the EuroQoL. Since filariasis is a disfiguring and disabling disease affecting the social life of the individual, the domain of social participation was incorporated into the 7D5L instrument.

It has been observed that there are some differences between the currently available disability weights for lymphatic filariasis estimated by the GBD group and the disability weights estimated by the present study. The GBD study gave disability weights for only two chronic health states of lymphatic filariasis (lymphoedema and hydrocele), while the epidemiological progression of the disease shows a wide spectrum of acute and chronic stages (Pani et al, 1995).

Health state valuations are by definition individual preferences between different health states. The disability weight used by the GBD

studies were derived from workshops mostly attended by medical and public health experts. This study has attempted to test the feasibility of determination of disability weight through the community. The results showed that the perception in the community of the severity of a disease was different from that of the medical experts. The community gave higher disability weight in all the health states of LF. This may be because medical experts consider only the morbidity of a health state, while the community takes into account social aspects, such as stigma and isolation due to the disease as well (Ottesen et al, 1997). The disability weight for bancroftian lymphoedema from the GBD study was 0.106, while it was 0.45 by experts and 0.85 by the community in this study. The GBD disability weight for H>15cm was 0.073, whereas this study showed a higher disability weight of 0.29 by the experts and 0.57 by the community.

Certain factors have arisen as a result of determining disability weights for diseases. Among them is the universal nature attached to disability weights. The disability weight associated with each health condition is currently fixed across all social, cultural and environmental contexts. Although the fixed disability weight is defended on grounds that it supports a strongly egalitarian flavour in the DALY, the lack of consideration of realistic contexts results in a measure that will underestimate the burden associated with morbidity in disadvantaged populations, and

overestimate the burden in advantaged populations (Essink-Bot et al, 2002). This argument seems logical and points towards the need to determine disability weights for diseases at a national level, which could then be used at a global level. Another issue regarding disability weight in this study is whose valuations should be considered, those of the medical experts or those of the community? These issues need to be further discussed.

### Conclusion

The findings of this study indicated that lymphatic filariasis may account for a considerably higher level of DALYs than previously thought, due to the lack of data on the acute and other stages of the disease. This study has developed an appropriate methodology to determine disability weights for different health states. Acute episodes of adenolymphangitis contribute maximum burden to filarial patients, and require appropriate management strategies in morbidity management towards elimination of LF. This study also emphasised the need for multicentric studies at national and global levels for standardisation of disability weights for estimating the burden. JL

### Key points

- ▶▶ Disability weight for seven different clinical manifestations of lymphatic filariasis has been derived which will be useful for more realistic estimates of disease burden using DALY.
- ▶▶ Acute episodes of adenolymphangitis imposes more burden, followed by advanced stages of filarial manifestation.
- ▶▶ Multi-centric studies will be useful to standardise disability weight at national/global level for more realistic DALY estimates.

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# PERCEPTION OF HEALTH STATUS OF PATIENTS WITH LYMPHATIC FILARIASIS

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## Abstract

**Background:** Assessment of health status can offer more insight into the different outcomes of lymphatic filariasis (LF) and provides an opportunity to strengthen the morbidity management programme, a component in the global elimination programme. **Aims:** To examine the accuracy of treatment providers' (experts) descriptions of the health outcomes of LF. **Methods:** A seven dimension five level (7D5L) instrument describing all the seven health domains of the disease was used. Fourteen medical experts participated in the study. The severity level for domains given by each respondent was converted to a domain score, ranging from 0 (no problem) to 4 (severe problem). The mean score of severity was calculated for each domain for a given health state. Overall severity score given by each respondent for each health state was calculated by adding the domain scores. The outcome of this assessment was compared with that reported by 174 patients with different clinical states of LF. **Results:** All the seven domains of health are affected by filarial disease, with the levels of severity varying with health states. Health status (HS) assessed by the experts was significantly lower than that of the patients. **Conclusions:** Experts could assess the magnitude of the health outcome of LF, but not the extent of patients' perceptions. The development strategy of home-based morbidity management of LF should consider the level of severity in different health domains perceived by the actual sufferers. **Declaration of interest:** None.

## Key words

Lymphatic filariasis  
Health status  
Morbidity management  
Treatment providers

Lymphatic filariasis (LF) is endemic in at least 83 countries with 1.3 billion people at risk of contracting it (World Health Organization [WHO], 2006). It is targeted for elimination globally by 2020 (WHO, 1997). Transmission control by mass annual single dose co-administration of diethylcarbamazine with albendazole, and limb care and hydrocelectomy for morbidity management are the recommended strategies to achieve

elimination. Guidelines to evaluate the impact of transmission control are available (WHO, 2004a), although there are certain issues to be addressed in the sampling procedure. A guideline is yet to be developed and validated for morbidity management (Krishna Kumari et al, 2007). The health status of individuals may be considered as one of the indicators that can be used to assess the impact of morbidity management. The psychological effects and social stigma associated with LF are immense (WHO, 1998) and, according to the WHO World Health Report (1995), are the second cause of long-term suffering, disability and morbidity (the first being mood affective disorder) (WHO, 1995; Durrheim et al, 2004). They also contribute to the economic burden of LF to individuals, communities (Gyapong et al, 1996; Dreyer et al, 1997; Ramaiah et al, 1997, 2000) and the healthcare infrastructure (Haddix and Kestler, 2000). Information on the severity of disability caused by LF in different domains of health is scanty (Suma and Shenoy, 2003) and is important not only for the improvement of the morbidity management package, but also for

development of advocacy and social mobilisation tools.

Health status (HS), a multidimensional profile of health (WHO, 2003) is the description of the health state of an individual (Andersen et al, 1998). It is based on a variety of domains reflecting physical, mental and social outcomes, and is primarily used for measuring the ability of an individual to perform activities required in daily life. In this study, we presented the health status of seven different clinical manifestations (health states) of LF from the experts' (treatment providers') perspective, to assess the extent of their perception of the real outcome of the disease.

## Methods Instrument

A seven domains and five levels (7D5L) descriptive instrument (Krishna Kumar et al, 2005; Harichandrakumar et al, 2006), and an extended European Quality of Life (EQ-5D) instrument (Euroqol Group, 1990) incorporating two more domains and increasing the number of severity levels from 3 to 5, was used to assess the health status of LF by experts. The

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seven domains included mobility, self-care, usual activity and pain/discomfort (physical aspect of health), anxiety/depression and cognition (mental aspect of health) and social participation (social aspect of health), based on the effect of the disease on different aspects of health. A pre-defined 5-point severity level was used across each domain, i.e. no problem, mild, moderate, severe and extremely severe problem.

### Health states

The following seven health states of LF were considered for the assessment of HS:

- ▶ Adenolymphangitis (ADL): recurrent attacks of fever associated with inflammations of the lymph nodes and/or lymph vessels
- ▶ Lymphoedema of limbs:
  - pitting, reversible oedema (lymphoedema grade I [L1])
  - non-pitting irreversible oedema with normal skin condition (lymphoedema grade II [L2])
  - non-pitting, irreversible, oedema of skin thickened condition (lymphoedema grade III [L3])
  - grade 3 condition with papillomatous changes (lymphoedema grade IV [L4]).
- ▶ Hydrocele:
  - hydrocele <15 cm diameter (grade I [H1])
  - hydrocele >15 cm diameter (grade II [H2]).

### Respondents (experts)

A total of 14 experts participated in the study. The experts' valuation was done through an interactive workshop at the Vector Control Research Centre, Pondicherry, India. The experts were given the seven health states of LF and asked to assess the health status by assigning severity levels across each domain using the 7D5L instrument from their perception obtained by their interaction with patients during treatment.

### Data analysis

The severity level for domains given by each respondent was converted to a domain score, ranging from 0 (no problem) to 4 (extremely severe). The mean score of severity was calculated for each domain for a given health state.

To compare the health states, the overall severity score (HS score) given by each respondent for each health state was calculated using the formula:

$$\begin{aligned} \text{HS score} &= \sum_i D_i, i=1,2,\dots,7 \\ \text{Mean HS score} &= \sum_j (\sum_i D_i) / n, i=1,2,\dots,7 \\ &\text{and } j=1,2,\dots,n \\ \text{HS score} &= \sum_i D_i, i=1,2,\dots,7 \\ \text{Mean HS score} &= \sum_j (\sum_i D_i) / n, i=1,2,\dots,7 \end{aligned}$$

where  $D_i$  represents the  $i^{\text{th}}$  domain score and  $n$  is the number of respondents (experts) that participated for the valuation of that particular health state ( $n=14$ ). The HS score would range from a possible minimum score of 0 (no problem in all domains) to maximum of 28 (extremely severe problem in all domains). To classify the health state according to the International Classification of Functioning, Disability and Health's (ICF) (WHO, 2001a) classification of impairments, the percentage of HS score of the severity of each health state was calculated as:

$$\text{Percentage of severity} = (\sum_j (\sum_i D_i) / n) / 28 * 100, i=1,2,\dots,7 \text{ and } j=1,2,\dots,n$$

The health states were then classified into five categories:

- ▶ no impairment (0–4%)
- ▶ mild (5–24%)
- ▶ moderate (25–49%)
- ▶ severe (50–95%)
- ▶ complete/total impairment (96–100%)

based on the percentage of severity according to ICF on impairments. The non-parametric Mann–Whitney U-test was used to compare the mean scores of severity.

### Results

All the 14 experts reported that LF affected all the seven domains of health. The severity scores assigned for different domains (domain score-ranges from 0 to 4) varied with the health states of LF (Table 1). Similarly, for a given health state of LF, the severity score for domains varied, indicating differential impact. Irrespective of health states, maximum severity was assigned on social participation followed by pain and anxiety. Experts assigned the highest severity score to L4 and the domain score (mean) was

ranging from 1.14 to 2.57 in different domains. This was followed by ADL, ranging from 0.93 to 1.93.

Comparison of scores between different domains showed that initial stages of lymphoedema, anxiety and pain received higher values of severity, culminating to restricted social participation which scored the highest score of severity. Similarly, mobility scored more as the disease progressed. The advanced stage of lymphoedema (L4) scored the maximum severity for social participation, followed by mobility and pain. A similar trend was seen for hydrocele. Pain was the predominant health domain affected by ADL and for the rest of the domains the severity was moderate. In H1 and L1, the experts were assigned maximum score for anxiety/depression and minimum for usual activities.

The HS scores for different health states of LF given by experts were calculated (HS score ranges from 0 to 28) and are depicted in Figure 1. HS score increases with the grades (progression) of lymphoedema (3.71–12.21) and hydrocele (2.14–8.14). Acute episodes of adenolymphangitis scored 10.93, which accounts for about 39% of the severity. Analysis of HS scores of different clinical manifestations showed that the severity score of L4 was significantly higher ( $P<0.05$ ) than that of the lower grades of lymphoedema and hydrocele (Figure 1). Similarly, the HS score of H2 is significantly higher ( $P<0.05$ ) than that of H1. The HS scores of L1, L2 and L3 are comparable, indicating that the increase in severity is gradual, corresponding to the progression of the disease. The value assigned by different experts for acute episodes of ADL was highly variable compared to other health states.

The severity scores derived for LF from the experts in this study were compared with those from our earlier report (Harichandrakumar et al, 2006), based on patients' perceptions. The experts assigned lower scores in different domains compared to patients (Table 2). The difference in scoring was high in ADL (2 to 3 times) and H1 (up to 4 times) in different domains. HS scores by experts were significantly less ( $P<0.05$ ) than

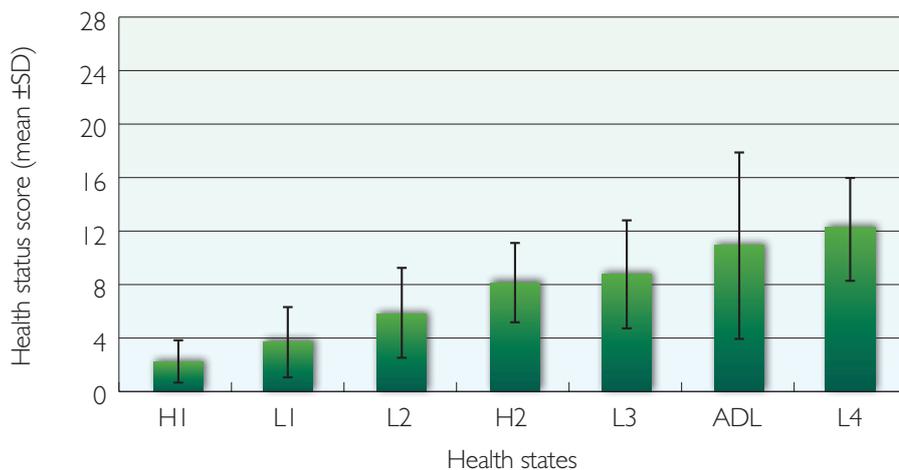


Figure 1. Health status score for different health states of lymphatic filariasis.

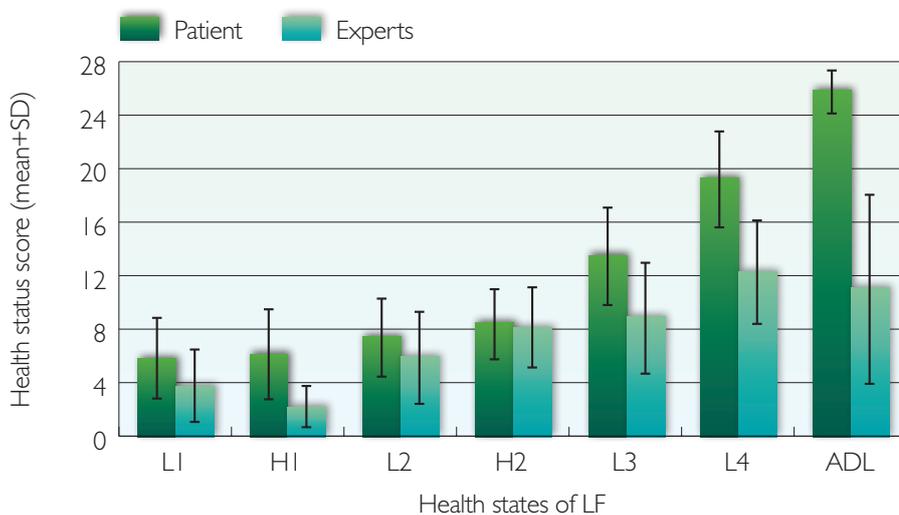


Figure 2. Comparison of health status scores assigned by the experts and patients.

patients' ratings, except for L2 and H2 ( $P>0.05$ ) (Figure 2). The HS score for H2 is almost equal, although for four of the seven health domains the severity scores assigned by the experts were higher than those reported by the patients.

In this study, classification of health states of LF into different categories of functioning, disability and health based on impairments measured as a percentage of severity from HS scores showed that L4 (43.6%), L3 (31.4%) and H2 (29%) and ADL (39%) were in the moderate category (Table 3). The rest of the health states of LF were in the mild category. Again, comparison of these values with those assessed by the patients showed that the experts' valuation was in a lower category in at least three health states.

### Discussion

Lymphatic filariasis manifests as different

clinical manifestations (health states). Acute episodes progress to chronic manifestations. Apart from grade I lymphoedema, all other stages/grades of LF are irreversible. This is due to permanent damage caused by the adult parasite in the lymphatics. Therefore, symptomatic treatment remains the choice of management. Acute episodes of ADL are known to be a precipitating factor for an increase in oedema, which further incapacitates those affected (Pani et al, 1995).

Morbidity management is an important component in the LF elimination programme (WHO, 2001b). Secondary infection (Dreyer et al, 1999) through 'entry points' in skin lesions of the affected limb is the main cause of fever and associated symptoms. Home-based limb care and foot hygiene are recommended for preventing such secondary infections

(WHO, 2006). Hydrocelectomy is currently the recommended method of correcting hydrocele and can be considered a permanent cure (WHO, 2004b; Addiss and Brady, 2007).

An understanding and awareness of health status, including physical, mental and social outcomes of the different stages of LF will help to strengthen the morbidity management package. This study identified the functional status of individuals with different health states and will help to develop suitable methods of intervention. Among the health domains affected by LF, social participation is affected the most, with a domain score of 2.57 for grade IV lymphoedema. During the initial stage of disease manifestation, anxiety and depression were the most dominant effects of LF. This could be due to the fact that early prevention remains the option of choice due to the irreversible nature of advanced stages. Another important aspect is that all the seven health domains were affected by LF and the severity increased with the grades of lymphoedema and hydrocele, indicating the complexity that develops with progression of the disease. Morbidity management efforts need to be intensified as the disease advances. Restriction of self-care and usual daily activities are another impact of the disease. More dependency leads to disruption of social integrity, limitation of social participation, loss of cognition and increased anxiety/depression.

Foot care is expected to address the problems related to the physical domains of LF, and counselling is essential to relieve concerns about the mental and social effects. Activities related to home-based management of morbidity should be carried out continuously at home, while counselling can be carried out at centralised healthcare facilities. The level of healthcare facility for such counselling can be identified based on the number of filarial patients in a given health unit.

### Conclusion

The findings of the present study show that the experts were able to assess the magnitude of the sufferings of patients, but not to the extent perceived by the patients. Therefore, experts cannot be used as an alternative source to

**Table 1**

**Severity score for different health states of LF in relation to health domains**

| Health state               | Health domains |           |                  |      |                    |           |                      | HS score | % severity |
|----------------------------|----------------|-----------|------------------|------|--------------------|-----------|----------------------|----------|------------|
|                            | Mobility       | Self-care | Usual activities | Pain | Anxiety/depression | Cognition | Social participation |          |            |
| Lymphoedema grade II (L2)  | 1.00           | 0.50      | 0.64             | 0.93 | 1.14               | 0.43      | 1.21                 | 5.86     | 20.92      |
| Lymphoedema grade III (L3) | 1.43           | 0.86      | 1.21             | 1.29 | 1.43               | 0.71      | 1.86                 | 8.79     | 31.38      |
| Lymphoedema grade IV (L4)  | 2.07           | 1.14      | 1.93             | 1.57 | 1.79               | 1.14      | 2.57                 | 12.21    | 43.62      |
| Hydrocele grade I (H1)     | 0.29           | 0.07      | 0.00             | 0.64 | 0.71               | 0.14      | 0.29                 | 2.14     | 7.65       |
| Hydrocele grade II (H2)    | 1.21           | 0.50      | 0.93             | 1.43 | 1.57               | 0.79      | 1.71                 | 8.14     | 29.08      |
| Adeno-lymphangitis         | 1.43           | 1.21      | 1.79             | 2.36 | 1.29               | 0.93      | 1.93                 | 10.93    | 39.03      |

**Table 2**

**Severity score assigned by the patients and experts for different health states of LF in relation to health domains**

| Health state               | Mobility                 |      | Self-care |      | Usual Activities |      | Pain |      | Anxiety/depression |      | Cognition |      | Social participation |      | HS score |       |
|----------------------------|--------------------------|------|-----------|------|------------------|------|------|------|--------------------|------|-----------|------|----------------------|------|----------|-------|
|                            | P                        | E    | P         | E    | P                | E    | P    | E    | P                  | E    | P         | E    | P                    | E    | P        | E     |
|                            | Lymphoedema grade I (L1) | 1.19 | 0.57      | 0.23 | 0.29             | 1.23 | 0.29 | 0.88 | 0.79               | 1.00 | 0.86      | 0.54 | 0.29                 | 0.69 | 0.64     | 5.77  |
| Lymphoedema grade II (L2)  | 1.39                     | 1.00 | 0.77      | 0.50 | 1.19             | 0.64 | 1.03 | 0.93 | 1.26               | 1.14 | 0.84      | 0.43 | 0.97                 | 1.21 | 7.45     | 5.86  |
| Lymphoedema grade III (L3) | 1.87                     | 1.43 | 1.52      | 0.86 | 2.22             | 1.21 | 1.96 | 1.29 | 1.91               | 1.43 | 1.74      | 0.71 | 2.26                 | 1.86 | 13.48    | 8.79  |
| Lymphoedema grade IV (L4)  | 2.45                     | 2.07 | 2.15      | 1.14 | 3.20             | 1.93 | 2.80 | 1.57 | 2.90               | 1.79 | 2.55      | 1.14 | 3.20                 | 2.57 | 19.25    | 12.21 |
| Hydrocele grade I (H1)     | 0.70                     | 0.29 | 0.30      | 0.07 | 1.22             | 0.00 | 0.78 | 0.64 | 1.30               | 0.71 | 0.48      | 0.14 | 0.89                 | 0.29 | 5.67     | 2.14  |
| Hydrocele Grade II (H2)    | 1.43                     | 1.21 | 0.35      | 0.50 | 1.78             | 0.93 | 0.83 | 1.43 | 1.83               | 1.57 | 0.65      | 0.79 | 1.48                 | 1.71 | 8.35     | 8.14  |
| Adeno-lymphangitis         | 4.00                     | 1.43 | 3.67      | 1.21 | 4.00             | 1.79 | 3.71 | 2.36 | 3.50               | 1.29 | 3.04      | 0.93 | 3.92                 | 1.93 | 25.83    | 10.93 |

P = patients' valuation; E = experts' valuation (Harichandrakumar et al, 2006)

filariasis patients themselves for gaining an understanding of the burden of the disease. In the authors' opinion, the morbidity management strategy recommended by the global programme

to eliminate LF (GPELFF) is based exclusively on the experts' perception, addressing only physical problems. This study clearly indicated the need to consider patients' perceptions when

developing a morbidity management package. To formulate an effective, acceptable and sustainable programme of morbidity management, there should be scope for improving the mental and

social aspects of health. Assessment of the health status of LF will also be useful in evaluating the effect of interventions on all three health domains (physical, mental and social). JL

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Key points

- ▶▶ Experts (treatment providers) could assess the health status of patients with filarial disease, but not to the extent of the patients' perceptions.
- ▶▶ Experts cannot be considered as proxy to patients in health status assessment.
- ▶▶ Morbidity management strategy of LF should include counselling of patients towards a better psycho-social life .

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Table 3

Comparison of health status score derived from patients and experts

| Health State               | Experts  |            |          | Patients* |            |          |
|----------------------------|----------|------------|----------|-----------|------------|----------|
|                            | HS score | % severity | Category | HS score  | % severity | Category |
| Lymphoedema grade I (L1)   | 3.71     | 13.27      | Mild     | 5.77      | 20.6       | Mild     |
| Lymphoedema grade II (L2)  | 5.86     | 20.92      | Mild     | 7.45      | 26.6       | Moderate |
| Lymphoedema grade III (L3) | 8.79     | 31.38      | Moderate | 13.48     | 48.1       | Moderate |
| Lymphoedema grade IV (L4)  | 12.21    | 43.62      | Moderate | 19.25     | 68.8       | Severe   |
| Hydrocele grade I (H1)     | 2.14     | 7.65       | Mild     | 5.67      | 20.2       | Mild     |
| Hydrocele grade II (H2)    | 8.14     | 29.08      | Moderate | 8.35      | 29.8       | Moderate |
| Adeno-lymphangitis         | 10.93    | 39.03      | Moderate | 25.83     | 92.3       | Severe   |

\*: Harichandrakumar et al, 2006

# AYURVEDA, YOGA AND SELF-CARE IN PATIENT-LED SUPPORT GROUPS

KS Bose, SR Narahari, GM Aggithaya, K Vivekananda, J Neethu, KS Prasanna

Lymphatic filariasis is a major public health problem in India but is neglected by the Government and private health care sectors. An estimated 23 million rural Indians are disabled by this disease. In the absence of active programmes for its treatment, the Institute of Applied Dermatology (IAD), Kasaragod, Kerala, has developed a low cost, self-care, home-based treatment by integrating locally available Indian systems of medicine (Ayurveda and yoga) into biomedicine. This intervention programme involves creating patient support peer group (PSPG) cooperatives and trains patients, patients' families, and paramedical workers in this self-care treatment involving local Ayurveda, yoga, Unani, Siddha and homeopathy (AYUSH). The programme can be implemented in a pan-Indian mode monitored by the IAD. It follows the Innovative Care for Chronic Conditions model developed by the World Health Organization (WHO, 2008) and aims to reduce disability and lost working days of patients through 'treatment empowerment', training, and community partnerships using self-care and home-based AYUSH interventions.

## Key words

Patient support groups  
Lymphatic filariasis  
Self-care  
Ayurveda  
Integrative medicine

The World Health Organization (WHO) has estimated that more than 80% of the world's population relies on traditional medicine for its primary health care needs (Bennerman et al, 1983). In India there are about 700,000 Ayurveda, yoga, Unani, Siddha and homeopathy (AYUSH) practitioners located in urban, semi-urban and rural areas. Although they are fully trained in aspects of preventive and curative care, their potential has not been fully realised in public health (Scheme of grant-in-aid for promotion of AYUSH intervention in public health). In 2003, Vaqas and Ryan recognised the potential of this ancient therapy for the treatment of lymphoedema.

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Previously there had been no example of a successful public health programme using traditional Indian systems of medicine (ISM) as a lead intervention. The Indian government has invited carefully targeted proposals aimed at strengthening the role of AYUSH in the public health system in India to ensure that ISM continues to serve the needs of the poorest in society, while also offering greater healthcare choices to those with the ability to pay. In response, the Institute of Applied Dermatology (IAD) in Kerala proposes to use AYUSH intervention to reduce the morbidity of an estimated 23 million rural Indians affected by lymphatic filariasis (LF), a vector-borne disease endemic in 15 Indian states, through training, telemedicine and public-private partnership.

## Lymphatic filariasis and its impact on the Indian poor

WHO classified elephantiasis, a symptom of LF, as a 'neglected disease of the poor' because there has been so little research into this tropical disease. Both the allopathic pharmaceutical industry and governments have ignored the causes of LF for too long. One-third of the world's LF patients live in India. Of the estimated 23 million patients with disability due to LF, Bihar (17%), Kerala (15.7%), and Uttar Pradesh (14.6%) are the most endemic. The seven states, namely Andhra Pradesh,

Bihar, Kerala, Orissa, Uttar Pradesh, Tamil Nadu, and West Bengal, contribute over 86% of LF carriers, and 97% of disease cases in the country (Agrawal and Sashidharan, 2006). Elephantiasis was described by Kaposi and Unna in the nineteenth century as a hypertrophy of tissue partly induced by damage to the lymphatics by bacterial infection and venous impairment. It causes appalling disfigurement with estimated losses of US \$1 bn annually to India's rural economy (Ramaiah et al, 2000). Most patients live in villages and have been disabled by their swollen legs and suffer repeated, additional episodes of fever. Many were their family's breadwinners before they had the disease.

The Global Alliance for Elimination of Lymphatic Filariasis (GAELF) is supporting an LF elimination programme through mass drug administration (MDA) to over 470 million Indians who are at risk of infection. The drugs kill parasites circulating in the blood and break disease transmission. However, the drugs have little effect on people who already have swollen limbs. Morbidity control has not yet been put into action as a major part of the GAELF programme. Likewise, the Indian government does not presently have any programme to help people who already have LF. Since morbidity control of this disease is mostly a neglected topic in the curriculum of medical schools

and it mainly affects the poor; private healthcare, including the multinational pharmaceutical industry, has shown little interest in managing this patient group. Therefore, patients with elephantiasis are not offered effective treatments and are often neglected.

The IAD proposal utilises Ayurveda and yoga to address this major public health problem, for which allopathy and biomedicine has only expensive solutions which are not yet available in India. The proposal has been developed following the Innovative Care for Chronic Conditions (ICCC) model developed by WHO (2008).

### Background of the proposed AYUSH intervention

A clinical management trials working group from GAELF recommended exploring the current practices of skin care in areas that are endemic with LF, as well as evaluating the effectiveness of traditional methods for lymphoedema treatment (Addiss et al, 2007). IAD developed a self-care, home-based, patient-led, ethical and evidence-based therapy combining Aurveda, yoga therapy and biomedicine on a pathophysiological basis (Narahari et al, 2007a; Narahari, 2007). This research was mentored by Professor Ryan (Emeritus Professor, Department of Dermatology, Oxford University Medical School) and was conducted as an extramural project of Kerala State Council for Science, Technology and Environment, Thiruvananthapuram (KSCSTE), during 2004–2005. Both the Indian Council for Medical Research (ICMR), New Delhi and KSCSTE supported the peer review of the pilot study for this treatment protocol during the first national seminar on Evidence-based and Integrated Medicine for Lymphatic Filariasis, other Chronic Dermatoses and HIV/AIDS in February 2005 (De, 2005). Later, the International Lymphology Society (ILS) awarded its president's prize to this study during the 20th International Congress of Lymphology held in Brazil (2005), and the ICMR discussed the protocol in the medical development congress (2006). This approach is supported by editorials in American and European journals

(Witte and Bernas, 2007; Moffatt, 2007). The brief details of AYUSH intervention also appear on WHO's web-based platform, Tropical Disease Research to Foster Innovation and Knowledge Application ([www.tropika.net](http://www.tropika.net)), created for the acquisition, review and sharing of current information and knowledge on potential innovations for interventions and control of infectious diseases of poverty). IAD treatment reduces disability and lost working days for patients with elephantiasis through 'treatment empowerment' and training.

**Since morbidity control of this disease is mostly a neglected topic in the curriculum of medical schools and it mainly affects the poor, private healthcare, including the multinational pharmaceutical industry, has shown little interest in managing this patient group. Therefore, patients with elephantiasis are not offered effective treatments and are often neglected.**

This initiative has demonstrated the efficacy and scientific basis of integrated self-care treatment in two previous national seminars (De, 2005; Narahari et al, 2007b). Another lead group involved in the development of treatments for lymphoedema in the East and West, the International Lymphoedema Framework (ILF), London, joined with IAD to organise the third national seminar in February 2008, to discuss the future strategies for morbidity management of lymphoedema in nations with high prevalence. The focus was the development of strategies for morbidity control of LF by patient empowerment through creation of patient support peer group (PSPG) cooperatives, using locally available AYUSH interventions and linking them to local AYUSH practitioners.

This proposal has incorporated the recommendations of the third

national seminar that was supported by Government departments: ICMR, DST, and KSCSTE.

### Goal of the project

The aim is to reduce the disability, impairment and handicap of swollen legs and frequent attacks of 'filarial fever' by using locally available AYUSH interventions so that patients are able to support themselves and be less dependent on their family members. Objectives include:

- ▶ Reducing disability and lost working days of poor LF patients through 'treatment empowerment', training and community partnerships using self-care and home-based AYUSH interventions
- ▶ To train AYUSH healthcare workers to empower patients to employ self-care of LF using AYUSH interventions
- ▶ Formation of patient support peer group cooperatives with LF patients and involving them in peer education, treatment empowerment and training of other patients.

### Patient support peer groups

The patient support peer groups aim to:

- ▶ Deliver inexpensive, high-quality services at home to the target group
- ▶ Develop a self-help attitude among patients with filariasis and encourage them to reach out to other patients
- ▶ Encourage patients to form a PSPG comprising family and people from the wider community
- ▶ Help patients who have undergone the treatment to take a lead role in training other patients.

It is hoped that these groups will be multiplied across the endemic states of the country by involving local small non-governmental organisations/ community based organisations (NGOs/CBOs).

### Treatment empowerment using self-care, Ayurveda and yoga

Motivated AYUSH practitioners, paramedical workers, NGO representatives and selected patients from endemic areas will be trained at

IAD, Kasaragod. Trainees will then form a PSPG in their locality with the help of local healthcare personnel and small NGOs/CBOs. The PSPGs will be given short-term local training programmes. The intervention will be monitored through a two-tier procedure using resource people (i.e. local members of the PSPG) and telemedicine. The PSPG will also be linked to local medicinal plant cultivators, suppliers, or develop home herbal gardens under a home herbal garden model developed by the Foundation for Revitalization of Local Health Traditions, Bangalore (Valiathan, 1990).

### Methods

AYUSH practitioners, paramedical workers, NGO representatives, patients and their family members, who are willing to help other people with the same disease, will undergo a structured institutional training programme at IAD. The effectiveness of the treatment will be seen by the changes to patients' swollen legs at the end of the training course. On successful completion of the course, the participants will be encouraged to form local patient support groups with the help of other patients, their family members and local healthcare personnel. Trainers of trainees (TOTs) will initially work closely with the central training centre at IAD, but it is hoped that they will develop a local network of AYUSH professionals and local healthcare institutions' support for the minimum medical needs of the programme, for example, limited outpatient care, ulcer management and infection control, psychosocial counselling, family counselling, spiritual counselling and, wherever necessary, institutional and inpatient care.

The authors' experience over the past four years has shown that the success of AYUSH intervention needs a well supported training centre with adequate resources to train the patients. Those patients who receive training (and also get treated for their disability as a part of the training protocol) will be an essential link to develop the local resource pool in each endemic area. Strong communication

pathways to monitor implementation in each endemic pocket using telemedicine and other forms of IT are essential. TOTs will train their peers along with local healthcare personnel. Academic links established with district/ taluka level social and health science schools will provide mutual support.

### Expected outcomes of the programme

Expected outcomes include:

- ▶ Empowering AYUSH health workers to treat an endemic disease in their locality in a public health programme
- ▶ Empowering patients to treat their own swollen legs under the broad framework of WHO's ICCC model
- ▶ Employing the local talents of yoga therapists, traditional herbal medicinal practitioners and masseurs
- ▶ Utilising AYUSH intervention for 'a neglected communicable disease'
- ▶ Alleviation of poverty and the provision of general employment opportunities by registering PSPGs under central/state government programmes to receive support for their livelihood (self-help groups in India can be registered as CBOs and are licensed by the government to start small income generation programmes of their own).

### Evaluations

The programme will be evaluated clinically:

- ▶ By recording baseline and follow-up photos of support group members
- ▶ By recording baseline and follow-up girth measurements
- ▶ By recording the frequency of episodes of filarial fever episodes.

Improvement in quality of life will be assessed:

- ▶ By noting the frequency of visits to a health clinic per year due to the patient's swelling
- ▶ By using the WHO Disability Assessment Schedule (WHODAS) ([www.who.int/icidh/whodas/index.html](http://www.who.int/icidh/whodas/index.html)).

The reorientation training for AYUSH healthcare personnel will also be evaluated by:

- ▶ Noting the number of patients employed following treatment empowerment training
- ▶ The number of AYUSH healthcare workers trained
- ▶ Links made to local healthcare institutions, including allopathic units, for basic healthcare needs.

### Discussion

IAD pioneered a low-cost, self-care AYUSH treatment that avoids long-term hospitalisation, expensive drugs or technical regulation to achieve the morbidity control of elephantiasis. Most of the components of the treatment involve traditional Ayurvedic skin care which requires little skill and only an occasional visit to a doctor's clinic. The expensive component of the treatment is the purchase of compression bandages, though their application can be taught to patients so that they can change their own dressings. This treatment is patient-centred, low technology and supports self-care. It emphasises partnership with LF patients and their families who are informed, motivated and armed with the requisite skills in the management and care of the chronically ill.

The proposed work has an advantage of integrating locally acceptable, familiar and prevalent systems of healthcare in a public health programme way. Patient empowerment enables it to be practised at home using local resources. The programme would popularise and demonstrate the effectiveness of 'self-care AYUSH intervention' as key to the development of health provision for LF in rural India. The proposal follows an ethos of involving patients and AYUSH healthcare workers in all aspects of the work undertaken.

Treatment in this proposed AYUSH intervention is cheap, easily provided after brief training, culturally sensitive, and capable of achieving widespread compliance (Witte and Bernas, 2007). Part of the programme will be centred on PSPGs enabling patients both to seek and gain employment, as well as receiving on-site care for their elephantiasis. Although it has

been proposed that local AYUSH practitioners will manage infection control measures, that are essential for preventing recurrent attacks of cellulitis and fever; this will also involve allopathic treatments. Inter-sector collaboration and an holistic approach to disease is practiced in other areas of medicine. However, compartmentalised systems of medical practice under various departments by the allopathic school such as dermatology, surgery, ENT (Kaur, 2007), a concentration of allopathic doctors in urban and semi-urban areas, as well as their non-cooperation with traditional ISM workers needs to be challenged at local level before the widespread dissemination of this programme. Availability of herbs and quality control of AYUSH interventions is another important issue. Unless measures are undertaken to ensure the regular supply of medicines, which are mostly cheap, the programme will be unable to meet the demand of the 23 million people with LF in India.

The experience at IAD of caring for more than 400 patients from seven Indian states has shown that the treatment can be successfully practised by the patients at home. Over 90% were satisfied during follow up. This treatment method will fit any environment, be it an academic medical centre or remote village (Witte and Bernas, 2007). Some patients may stop treatment but resume it when the swelling recurs. They also learn to manage infection through entry points, either by visiting the local allopathic doctor or by taking antibiotics. Longitudinal analysis of the treatment outcome in IAD using ANOVA (Narahari et al, 2007a) also showed statistically significant results.

The proposed work is a successful representation of the ICCC model developed by WHO (Public Health Foundation of India [PHFI], 2008). The PHFI also supports the concept of involving AYUSH experts from the endemic areas for rural healthcare. According to Rjat Gupta, its chairman, PHFI tries to train the people already working in remote areas. Further, using allopathic-trained healthcare providers

who were forced into community activities by the Department of Preventive and Social Medicine during their training has failed in its objectives. However, collaborating with allopathic establishments to control infection does not oppose the Ayurvedic principles and should be encouraged (Sushruta samhitha, Sutra sthana.Ch 4.Verse no 7).

In the absence of any successful medical intervention or major morbidity control programme for LF, AYUSH can make an impact to one of the more difficult areas of public health care in India. The proposal discussed in this article aims to achieve disability control of the many millions of people with LF in India by involving AYUSH-trained healthcare workers with a proven treatment programme using PSPGs. 

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### Key points

- ▶▶ 23 million are disabled by lymphatic filariasis causing an annual loss of US \$1 billion to Indian rural economy.
- ▶▶ Integrated, self-care, home-based and low cost treatment developed by the Institute of Applied Dermatology (IAD) is a proven treatment that can be administered after a brief training in resource-poor settings.
- ▶▶ Disability reduction and improvement in quality of life are the recommended outcome measures when this treatment is implemented at patient support peer group (PSPG) level
- ▶▶ The experiment can be replicated by adapting to local needs in any developing country endemic to lymphoedema.

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# EMPOWERING PEOPLE WITH DISABILITIES CAUSED BY FILARIASIS

GB Acharya, S Pati

The Lymphatic Filariasis Project at Satyabadi, India was set up in 2006 with the aim of empowering people affected by lymphatic filariasis so that they could exercise the right to live without discrimination in society, be entitled to have a livelihood and access to public services. Since then the project has set up self-support groups to educate patients about personal care and protective and preventive measures. The wider community has also been educated about the disease. The project has also given financial support to sufferers to help them to continue to earn a living. The project has yielded many positive results and continues to improve lives in this particularly endemic area.

## Key words

Lymphatic filariasis  
India  
Self-support groups  
Empowerment  
Education

Lymphatic filariasis (LF) is a neglected, chronic, vector-borne, infectious disease which is responsible for considerable suffering, deformity and disability, mostly affecting the lower socioeconomic groups in endemic areas. About 554 million people in 243 districts of India are at risk (World Health Organization, 2006). In Orissa, the fourth most endemic state in India, 20 of 30 districts are more affected. Coastal districts are more commonly affected, in which Puri tops the list. Satyabadi is one out of 11 blocks of the Puri district that has high endemicity. It is here that LEpra has implemented one of its projects entitled, 'Empowering Disabled People due to Filariasis'.

The project began in November 2006. It was funded by Guernsey Overseas Aid until September 2007, and thereafter, it continued with LEpra-UK support.

Satyabadi has a population of about 1,10,000 and, as well as exposure to filariasis, the locality is exposed to malaria, gastroenteritis, helminthiasis and other infections due to poor sanitation in the area. Within the area there are four health institutions and 14 sub-centres which provide primary healthcare services. Traditional practitioners and a few private practitioners provide alternative care. There are many submerged areas, ponds and pools with water-hyacinths which facilitate vector mosquito breeding. The main vector for filariasis in general is the *Culex quinquefasciatus* (77%) (Das et al, 1998), and filarial parasites are the *Wuchereria bancrofti* and *Brugia Malayi* (Mahapatra et al, 2007). Substantial human suffering, economic deprivation and social problems undermine the quality of life for people in this area. Understanding these problems, LEpra, with its history of quality disability management of people with leprosy, came forward to develop a model of care for lymphatic filariasis.

## Goal of the project

The overall goal of the project is for people affected by LF to have the right

to live without discrimination in society, to be entitled to a livelihood and access to public services. The project's objectives are:

- ▶▶ To form self-support groups (SSGs) and empower people with knowledge about personal care, protective and preventive measures against LF and to create awareness of the disease in society
- ▶▶ To help keep links between local government and non-government leaders to maintain successful management.

## Activities of the project

The key activities of the project include situational analysis, formation and maintenance of patient support groups, capacity building, model service provision, information, education and communication, helping people to continue working and providing links and coordination with wider health programmes.

## Situational analysis

All the households in the 94 villages of the block were visited to record details regarding the number of people with LF and their grading, along with their demographic and socioeconomic status. This revealed that about 3% of the total population (n=3,315) had elephantiasis and hydrocele, out of which 1,940 were male and 1,375 were female; 88% were more than 30

years old. Of these sufferers, 1,322 were stage I (swelling appears in the day and disappears the next morning), 994 in stage II (swelling persists) and 206 in stage III (swelling progresses with complications); 793 persons had hydrocele. Elephantiasis of the vulva and breasts was not surveyed.

#### Formation and functioning of self-support groups

A self-support group (SSG) was set up in every Gram Panchayat (GP) (village-level local government body), made up of 8–12 people comprising patients, an accredited social health activist (ASHA), and an Anganwadi worker (AWW). These are village level volunteers from the Integrated Child Development Scheme (ICDS) who look after children under the age of six, pregnant women and nursing mothers. These groups aim to strengthen skills and self-care practices for people with LF within the locality and spread messages for prevention of the disease. Twenty-two SSGs have been formed in the Satyabadi block.

#### Capacity building

The core idea of the project is to strengthen the community's capability to prevent and manage LF, and to help the general healthcare workers to provide appropriate services and guidance. With this in mind, community mobilisers and volunteers were trained in the prevention and management of LF. Thirty-six general healthcare (GHC) staff (health workers = 36; health supervisors = 4), 85 ASHA workers, 104 health volunteers in Satyabadi and 56 government and non-government doctors in Puri district were trained by experts.

#### Model service provision

A model referral centre that provides optimal treatment and care to patients with LF and supports general healthcare staff and other volunteers has been established in the government-run 'Area Hospital' at Sakhigopal, where the medical consultant of the project and medical and paramedical staff of the hospital provide the services. To date, more than 1,200 patients have attended the hospital and been provided

with services (Figure 1). The capacity building programme of medical officers and paramedical staff was also conducted at the hospital where 110 affected people in the very low socioeconomic group have been provided with impregnated mosquito nets. It is hoped that other people in the community will be encouraged to use mosquito nets regularly.

#### Information, education and communication

The project has a strong grounding in information, education and communication. The people were educated in the prevention and management of LF by the following processes. 220 SSG members, 610 Panchayat Raj institution (PRI) members and many non-government organisation (NGO), community-based organisation (CBO) and Mahila Mandal (women's groups) members were educated so that they could pass on information to patients and the wider community. Moreover, 3,757 school students, 256 teachers from 20 schools were also educated (Figure 2).

Other approaches included 22 street-plays (roadside entertainment performed by artists, giving a robust message to the community for better health-seeking behaviour); 17 Palla performances (another mode of indigenous entertainment based on a mythological subject being performed by a group of artists); three exhibitions (different educational materials displayed at special festivals or occasions when large numbers of people come together in a particular place on LF transmission, preventive methods and self-care practices); Miking (six rounds) (this is a propaganda campaign. In this case, people were requested through a loudspeaker to take part in a mass drug administration [MDA] campaign); 110 group meetings (Figure 3); 44 murals; 600 banners and posters; distribution of 5,000 leaflets; and eight health camps (641 patients with elephantiasis and complicated LF who could not attend hospitals were asked to assemble in a public place where they could be examined and skin care methods were demonstrated).



Figure 1. Patient care services.



Figure 2. School students attending an LF awareness programme.



Figure 3. Awareness programme for patients with lymphatic filariasis.

#### Supporting patients' livelihoods

Due to chronic disabilities, people affected by LF are often unable to work and are forced to live in very poor conditions. The disease also contributes to substantial physical and financial problems. The project aimed to raise the financial status of some LF patients through the following processes:

- ▶▶ By giving a socioeconomic rehabilitation (SER) loan to 44 beneficiaries to assist in re-employment in jobs involving milk products, goats, poultry, ducks, stone-carving, coconut businesses, coir making, rice-vending and making broomsticks (Figures 4–6)
- ▶▶ By supporting Mahila Mandal to generate employment by cleaning a five-acre pond which was covered with weeds and is now used to cultivate fish and a duckery.



**Figures 4–6. Socioeconomic rehabilitation (SER) loans have been given to people with filariasis to help them to retain their livelihood in jobs such as dairy farming, making broomsticks and poultry.**

#### Links and coordination

The initiation of MDA (diethylcarbamazine [DEC]) has been successful. The coverage of the MDA was 93% in 2006 and 95.3% in 2007, against the state average of 60%. GHC staff were repeatedly motivated to keep a good rapport with the community as regards prevention and self-care practices for LF. PRI members, SSGs, self-help groups, Mahila Mandal, NGOs, CBOs were helped to facilitate governmental and non-governmental facilities for people in the lower socioeconomic groups.

#### Evaluation

During the last quarter of 2007 an internal evaluation of 1,220 patients revealed that 1,032 (84.6%) had some working knowledge of self-care practices and 127 (10.4%) patients continued them regularly. It is hoped that a good proportion of LF patients will continue the self-care practices that they have learnt from this project.

#### Challenges

Only 10% of patients are now practicing self-care. This needs to be worked upon and increased to at least 50%. Although the practice of using mosquito nets has improved, this needs to be further reinforced through behavioural change communication (BCC), integrated healthcare services and inter-sectoral coordination between different departments of government, NGOs, CBOs, self-help groups, self-support groups and the community at large. Although there is some awareness on mosquito breeding, people do not actively try and prevent it. This also needs further reinforcement.

#### Conclusion

This project is the only one of its kind in Orissa. It has yielded many good results, such as:

- ▶▶ Helping those with LF to know that they have a right to a better quality of life through involvement with SSGs
- ▶▶ Preventing mosquito breeding and mosquito bites
- ▶▶ Taking care of swollen body parts and teaching self-care
- ▶▶ Supporting and making links for income generation for needy and affected people
- ▶▶ Increasing awareness of the disease in the wider community.

It has also explored some new areas for intervention. A larger project embedding the whole district that includes multi-sectoral involvement and public-private partnership should be taken up in the endemic areas, so that the quality of life of affected people can be further improved. JL

#### Key points

- ▶▶ Lymphatic filariasis is a neglected, chronic, vector-borne, infectious disease which is responsible for considerable suffering, deformity and disability, mostly affecting the lower socioeconomic groups in endemic areas.
- ▶▶ In 2006, a project called 'Empowering Disabled People due to Filariasis' was set up in Satyabadi, a particularly affected area in India.
- ▶▶ The overall goal of the project is for people affected by lymphatic filariasis to be allowed to exercise the right to live without discrimination in society, to be entitled to a livelihood and access to public services.
- ▶▶ The project's objectives are to form self-support groups (SSGs) and empower people with knowledge about personal care, protective and preventive measures against LF and to create awareness of the disease in general society.
- ▶▶ The project has yielded many positive results.

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# MANAGEMENT OF AIDS THROUGH SWASTHA VRITTA

Dr Galib, BJ Patgiri, PK Prajapati

Ayurveda, the most ancient scientifically codified system of medicine, discusses both preventive and curative aspects of diseases in a comprehensive way. The system advocates guidelines for the attainment of a long, healthy and happy life based on *swastha vritta* (a modified code of life). Theories of disease manifestation, modes of transmission and their management, are exclusively dealt with in the classical literature. Concepts of communicable diseases can be viewed through theories like *agantuka roga* (diseases of external origin), *janapadodhwamsa* (natural calamities) and *krimi* (worm infestations). Ayurveda emphasises that if an individual controls his feelings, desires and mind, and follows a prescribed code of noble conduct, he will remain healthy. This paper explores this way of life with special emphasis on acquired immunodeficiency syndrome (AIDS).

## Key words

AIDS  
Ayurveda  
Communicable diseases  
Lifestyle

The Alma Ata Conference in 1978 called all governments to achieve 'Health for all the citizens of the world by the end of 2000'. Despite the availability of sophisticated technology and facilities, as well as spending a great deal of money, this could not be achieved because of a number of life-threatening diseases, such as acquired immunodeficiency syndrome (AIDS). AIDS, a degenerative disease of the immune system, is a serious medical and social issue which threatens the populations of all developing countries, including India. The medical field and many pharmaceutical companies are

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still struggling to find an effective drug for the prevention or cure of this disease. If they succeed and new drugs are launched, as like as not these will be expensive and unaffordable for the vast majority of people who are positive for human immunodeficiency virus (HIV). Moreover, these synthetic drugs can only prevent the replication of the virus, they cannot help to improve immunity and quality of life. Hence, we are looking for better alternative sources, and it is here that Ayurveda can play a pivotal role.

AIDS is a relatively recent disease and, as such, cannot easily be compared with any of the ancient pathological criteria used in Ayurveda. However, AIDS is a communicable infectious disease and the concepts of such infectious diseases can be traced back to the vedic period of Indian history and viewed through three headings in Ayurveda:

- ▶ *Agantuja rogas* (diseases of external origin)
- ▶ *Janapadodhwamsa* (natural calamities including endemics and pandemics)
- ▶ *Krimi* (worm infestations).

The celebrated ancient text of Ayurveda, familiarly known as *Charaka Samhita*, discusses communicable

diseases in the following ways:

- ▶ *Agantuja rogas* because of external factors like *bhootopasarga* (coming in contact with evil spirits/microorganisms), *visha* (toxic substances, pollen, etc.) and *abhighata* (accidents, injuries, etc.) (Acharya Yadav Ji Trikam Ji, 2000a)
- ▶ *Charaka* again mentions that *bhutas* (infectious organisms) like *rajani chara* destroy the *ojas* (the vital essence of the body, which is the power that resists disease formation) and, as a result, the *bala* (immune responses) of the individual decrease and he/she becomes bedridden (Acharya Yadav Ji Trikam Ji, 2000b)
- ▶ Interestingly, Chakrapani (Acharya Yadav Ji Trikam Ji, 2000c) classifies the aetiological factors of the disease manifestation into two. One is *sadharana* (general/ common to every one), and the other is *asadharana* (specific). The *asadharana* type of aetiological factor varies from person to person (depending upon the conduct of the individual)
- ▶ Another interesting reference can be located at *Charaka Vimana Sthana*, where the ancient seer mentions the role of *bhuta avेशa* (afflicted with microorganisms) in the manifestation of epidemics

- ▶ In the same chapter, Charaka goes on to emphasise the role of *ashuchi* (unhygienic practices) and *adharmā* (bad conduct) as causes for diseases, particularly epidemics (Acharya Yadav Ji Trikam Ji, 2000d)
- ▶ At another instance, the seer says that *pragyaparadha* (indulging in unwholesome activities intentionally or by ignorance, or lack of understanding) leads to *adharmā*, which will become the root cause for the manifestation of various diseases (Acharya Yadav Ji Trikam Ji, 2000e)
- ▶ The seer repeatedly advises against indulging in sexual activities with strangers, which can lead to complications (Acharya Yadav Ji Trikam Ji, 2000f)
- ▶ Further, the seer clarifies that if the person is infected, the disease will also be transmitted to his wife and progeny (Acharya Yadav Ji Trikam Ji, 2000g).

Another ancient classic of Ayurveda, *Sushruta samhita* focuses on communicable diseases:

- ▶ Just like Charaka, Sushruta stresses the role of *adharmā* (bad conduct) in disease transmission (Acharya Yadav Ji Trikam Ji, Acharya Narayan Ram 1980a). It is interesting to observe the clarification of disease transmission provided by Dalhana as being of two kinds. One is through inhalation and the second from inoculation through skin/mucous membranes (Acharya Yadav Ji Trikam Ji, Acharya Narayan Ram 1980b)
- ▶ Sushruta gives clearer information about the concept of infectious/communicable diseases and says that sexual contact, touch, and inhalation promote transmission of diseases like *kusta* (various skin lesions), *jwara* (different varieties of fevers), *shosha* (emaciation), and *netra abhishyanda* (conjunctivitis) from one infected person to another (Acharya Yadav Ji Trikam Ji, Acharya Narayan Ram 1980c)
- ▶ Again, the seer emphasises the role of sexual perversions in disease transmission (Acharya Yadav Ji Trikam Ji, Acharya Narayan Ram

1980d). The reference says that indulging in sexual activities with a woman who is *vyadhi pidita* (diseased), or who is having *dusta yoni* (suffering with infections of the genital tract), and *ati prasanga* (an inclination towards sexual relationships, particularly with strangers) leads a man towards death

- ▶ Susruta says that there was a *visha kanya* (a vivacious seductive woman with poison in her body), who seduced the enemy king and killed him by developing sexual relations (Acharya Yadav Ji Trikam Ji, Acharya Narayan Ram 1980e). One may ask whether the *visha* is any infectious organism? Was she transmitting HIV infection?

All these references clearly reveal knowledge of 'disease transmission' during ancient days (Table 1). Researchers today accept the views

of Charaka and Sushruta and view *ati prasanga* (sexual perversions), *ashuchi* (unhygienic practices/sharing infected, contaminated needles, transfusion of HIV positive blood) and *adharmā* (not following *swastha vritta* [a modified code of life]) as being responsible for the manifestation of AIDs.

Due to the above mentioned *nidana* (aetiological factors), organisms that cause disease enter the body and attack the individual. As a result, the *rasadi dhatus* (the physiological entities) of the individual will get vitiated and symptoms of disease follow (Acharya Yadav Ji Trikam Ji, 2000h). If left untreated, these become *jirna* (chronic) and settle deep into the *gambhira dhatus*. Further, *pranayatana*s (vital organs of the body) and *ojas/bala* (*vyadhi ksamatva* — immune responses) get involved, settle into *ojo ksaya*, which in turn, kills the individual (Acharya Yadav Ji Trikam Ji, 2000i; Acharya Yadav Ji

Table 1

Factors of disease transmission and probable comparison today

| Nidana  | Reference                       | Probable comparison  |
|---|---------------------------------|--|
| <i>Bhuta avesha</i>                                       | Cha Vi 3/6; Cha Sha 2.9         | ▶ Afflicted with microorganisms, such as virus, fungi, bacteria  |
| <i>Prasanga</i>   | Su Ni 5/33–34; Cha Su 8/22      | ▶ Unfaithful sexual relationships<br>▶ Having multiple sexual partners<br>▶ Unprotected sexual contact                           |
| <i>Ati Prasanga, Anya Yoni, Dusta Yoni, Vyadhi Pidita</i> | Cha Chi 30/135<br>Su Chi 24/115 | ▶ Excessive indulgence in sexual activities with a woman who is infected or diseased<br>▶ Inclination towards sexual perversions |
| <i>Ashuchi</i>  | Cha Vi 3                        | ▶ Unhygienic practices (sharing infected and contaminated needles, transfusion of HIV-positive blood)                            |
| <i>Adharma</i>  | Cha Vi 3/6                      | ▶ Bad conduct of society (immorality, perversions and anti-social behaviour, etc)  |
| <i>Pragyaparadha</i>                                      | Cha Sha 1/102                   | ▶ Indulging in unwholesome activities intentionally or by ignorance, or because of lack of understanding                         |
| <i>Visha Kanya</i>  | Su Kalpa 1/6                    | ▶ Sexual relationships with a seductive woman who is infected with disease   |

Trikam Ji, Acharya Narayan Ram 1980f). With this in mind, a few conditions explained in Ayurveda, such as *ojo ksaya/pratiloma ksaya/vyavayaja shosha* can, to some extent, be compared with AIDS.

### Chikitsa (treatment patterns in Ayurveda)

Ayurveda has many medicines with special properties, such as purifying the *srotases* (body channels), stimulating the metabolism and improving quality of life. These medicines in Ayurveda are known as *Rasayana* drugs. Today, they are labelled as immunomodulators, adaptogenic drugs (i.e. natural products that increase the body's resistance to stress, trauma, anxiety and fatigue). Examples of such drugs include; *Kalamegha* (*Andrographis paniculata*), *Yastimadhu* (*Glyceriza glabra*), *Chitraka* (*Plumbago zeylanicum*), *Bhunimba* (*Swertia chirata*), *Guduchi* (*Tinospora cordifolia*), *Nimba* (*Azadarachta indica*), *Musta* (*Cyperus rotundus*), *Amlaki* (*Embllica officinalis*). In the authors' opinion, used judiciously, they could be of great help to many illnesses.

All these drugs, by virtue of their immunomodulating, antioxidant and other related activities, help to stimulate either specific or non-specific immunity, or both. A combination of all these drugs would, therefore, have a diverse effect on various aspects of the immune system and improve the health of tissues and organs. Ultimately, the quality of *ojas* will get improved which, in turn, improves quality of life.

*Rasayana* is one of the special branches of classical Ayurveda. Apart from drugs, this procedure advocates dietary regimens and special health-promoting behaviour known as *acara rasayana* to develop immunity against diseases. It also advocates an improved code of *acara* (socioeconomic behaviour), such as respect towards elders, practising meditation, holding onto truth, non-violence, avoiding alcohol, anger, excessive indulgence in sex and keeping free from emotional disturbances. Probably, this less stressful, modified lifestyle with pronounced anabolism leads to health and happiness.

These immunomodulatory drugs if prescribed with *swastha vritta* (modification of lifestyle, special diet, exercise and psychological support) show remarkable effects. *Swastha vritta*, the wisdom of Ayurveda, armed with *dinacharya*, *ratricharya*, *ritucharya* along with the *ahaara*, *vihaara* according to *Desha* (place), *Kaala* (season), *Prakriti* (individual constitution) can provide protection against illnesses such as AIDS.

The non-expensive measures of *acara rasayana* can help individuals to develop resistance against diseases, if followed as specified in the classics.

### AIDS begins where safety ends and AIDS ends where safety begins. Hence, safety becomes the first and best preventive aspect.

In Ayurveda, the holistic concept of health pays great attention to the mind. All body functions are under the influence of the mind. It is clearly stated that emotional imbalances lead to disease manifestation (Acharya Yadav Ji Trikam Ji, 2000j). These imbalances produce disturbances in the autonomic system which, if prolonged, lead to disease. Studies have suggested that mood endorphins get released in joyful conditions, producing positive thoughts; on the other hand, misunderstandings, grief, anxiety and fear promote the release of catecholamines, which trigger symptoms of disease. Patients with AIDS can become afraid and nervous, but training in meditation and positive thinking can make the work of the physician easier. Further, prescribing moderate exercises and *yogasanas* helps to counteract stress, anxiety and depression, facilitating better coping skills.

Furthermore, by engaging in aerobic conditioning or behavioral restructuring, the individual will gain a sense of commitment to his or her health. These interventions provide a sense of empowerment and improve self-esteem. Without them, events

occur to decrease the immunological and endocrine functioning of the individual.

### Ahara (food supplements)

As mentioned by Chudamani Mishra (Aacharya Gulraj Sharma) 'The individual is supposed to take *kseera* (milk and its products), *mamsa rasa* (meat juice and its other derivatives) and *madhura rasa pradhana ahara* (the diet which is highly carbohydrate in nature)'. This combination provides a highly nutritious diet. Prior to initiating this nutritious diet, the individual's *agni* (enzymatic hormonal functionings) are examined and improved with appropriate diets (Acharya Yadav Ji Trikam Ji, 2000k). Once the *agni* has improved, the formation of *prashasta dhatu* (healthy tissues) will follow. Thus, *agni* should also be considered while treating AIDS-related symptoms.

After looking into these guidelines, it can be concluded that *Upastambhas*, i.e. *ahara* (properly planned diet), *swapna* (sleep) and *brahmacharya* (self-control) play a pivotal role in stabilising the functioning of *ojas* in normal conditions. Hence, adopting *acara rasayana* along with other simple measures as described in the classics under *swastha vritta*, can go a long way to fighting AIDS.

### Preventive measures

AIDS begins where safety ends and AIDS ends where safety begins. Hence, safety becomes the first and best preventive aspect.

In the authors' opinion, AIDS is a disease of an unhealthy lifestyle. The ancient Ayurvedic seers placed a great deal of emphasis on leading a good, morally uplifting life as a means of preventing diseases. *Table 2* describes a few of the preventive measures focused upon in the classics that are relevant to HIV/AIDS today:

### Conclusion

The role of sexual perversion, immorality, antisocial behaviour, or unhygienic practices have been repeatedly stressed since the vedic

**Table 2**

**Preventive measures for HIV/AIDS**

| Measure  | Types of modification  |
|--|--|
| Avoid <i>pragyaparadha</i>   | ▶▶ Control over sense organs and mind, proper remembrance, correct knowledge of place, season and one's self plays a pivotal role in maintenance of an individual's health   |
| Follow: <i>dina charya</i> (daily regimen) and <i>ritu charya</i> (seasonal regimen)<br>Take <i>shadrasa ahara</i> (balanced diet) | ▶▶ The classical guidelines specified that following daily and seasonal regimens and eating a balanced diet would help to boost the immune system of the body  |
| Avoid <i>adharma</i> (bad conduct)   | ▶▶ In the context of AIDS/HIV, <i>adharma</i> can be compared with antisocial behaviour, immorality and perversion, important aspects of disease manifestation and transmission<br><br>▶▶ Avoid unhygienic practices, an important factor in disease transmission  |
| Sexual health  | ▶▶ One should not indulge in sexual activities with a woman who is infected or diseased, or who has a history of bad conduct<br><br>▶▶ It is not appropriate or acceptable to have sexual contact with unknown personalities (prostitutes)<br><br>▶▶ One should not indulge in sexual activities with a person or a woman who is a stranger, because practically it is always difficult to know the secrets of a person's sexual past<br><br>▶▶ One should not have sexual perversions. <i>Anya Yoni</i> (sodomy, etc) is mentioned as punishable in Vedas, which is more dangerous for HIV transmission |

period in the context of various diseases. The classics recommend that one should always follow *swasta vritta* (*dharmadina charya* schedules of good conduct) strictly, as this helps to prevent communicable diseases/*akala mrityu* (accidental death).

Lastly, widespread beliefs and misconceptions are also factors. For example, a few years ago, two children in Kerala (the state which takes pride in its high literacy rate) were denied admission into school because they were HIV positive. This indicates that general awareness programmes and counselling sessions are needed. Those people who are HIV positive are not

a threat to society and should be able to live as other members of the community. JL

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Acharya Yadav Ji Trikam Ji (2000e) *Agnivesha's Charaka Samhita, Sharira sthana* 1:102. Chaukhamba Surbharati Prakashan, Varanasi

Acharya Yadav Ji Trikam Ji (2000f) *Agnivesha's Charaka Samhita, Sutra sthana* 8:22, *Sharira sthana* 1:103 *Chikitsa sthana* 8:24 and 30:184–185. Chaukhamba Surbharati Prakashan, Varanasi

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# IMPACT OF LYMPHOEDEMA ON PATIENTS' LIVES

PA Morgan

This brief paper reviews the health-related quality of life (HRQoL) literature in order to assess the impact of lymphoedema on the lives of patients. Typically, the evaluation of HRQoL attempts to capture the impact of health and illness on a person's physical and mental well-being, as well as on their ability to function socially (Fallowfield, 1990). Its importance lies in the shift away from traditional practitioner-determined outcome measures (Cheater, 1998) to focus on the patient's perspective and how both illness and treatment can impact on daily life (Hawthorn, 1993). Equally important is that quality of life data have the potential to inform the physical, psychological, social, spiritual and economic aspects of caring (Ferrell et al, 1997; Ferrell et al, 1998).

## Key words

Health-related quality of life  
Literature review  
Patient experience  
Psychosocial implications

Information for this paper was gathered from articles referenced through Medline, EMBase and Cinahl using key words 'lymphoedema and quality of life', 'chronic oedema and quality of life', 'psychosocial and lymphoedema' and 'patient experience and lymphoedema'. The search results were categorised into three broad areas:

- ▶ Qualitative research
- ▶ Cross-sectional studies
- ▶ Longitudinal and outcome studies.

The criterion for inclusion was, in the case of quantitative studies, the investigation of quality of life for people suffering from lymphoedema. Only studies which have the effects of lymphoedema on quality of life as their primary focus were considered eligible.

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For qualitative studies, the criteria encompassed research that explored the quality of life of patients with lymphoedema, the patient experience of lymphoedema and the psychosocial implications of the condition.

## An overview of the review of the literature

### Qualitative studies

Qualitative research approaches attempt to achieve a deeper understanding of the impact that

## Information for this paper was gathered from articles referenced through Medline, EMBase and Cinahl using key words 'lymphoedema and quality of life', 'chronic oedema and quality of life', 'psychosocial and lymphoedema' and 'patient experience and lymphoedema'.

lymphoedema can have on the lives of patients. These studies act as a window on the experience of lymphoedema from the patient's perspective and provide powerfully subjective accounts which can contribute to more holistic and sensitive treatment and care decisions.

Of the seven qualitative studies reviewed, one was conducted in Australia, four in the UK, one in the United States of America and one in Sweden. These studies are shown in *Table 1* and referenced at the end of this paper.

### Cross-sectional studies

There are few cross-sectional studies that evaluate the impact of lymphoedema on health-related quality of life (HRQoL). The five studies reviewed here use a variety of generic tools and methods. Two studies were undertaken in the UK, one in France, one in the USA and one in Brazil. These studies are given in *Table 2*.

### Longitudinal studies

As with cross-sectional studies, longitudinal studies have favoured the use of an array of tools that assess a number of different aspects of quality of life as outcome measures for a variety of interventions. Across the eight longitudinal studies reviewed, ten different tools are used, often in combination and, in some cases, with complex methodologies making comparison between studies difficult (*Table 3*).

### Broad findings

A number of broad findings can be

identified from this review. These are:

- ▶ The physical and emotional effects of lymphoedema
- ▶ The relationship between the implementation of evidence/consensus-based, patient-centred guidelines for the management of lymphoedema and improved HRQoL
- ▶ The positive influence on HRQoL of a planned combination of intensive treatment, patient education and ongoing support for self-management on HRQoL.

**Focused findings**

More focused findings include the identification of factors associated with lymphoedema that can lead to deficits in HRQoL. These include:

- ▶ Poor information
- ▶ Poorly informed healthcare professionals
- ▶ Inadequate specialist services
- ▶ The frequency of cellulitis
- ▶ The presence of pain and discomfort
- ▶ The condition of the skin
- ▶ Lymphoedema in the dominant hand
- ▶ Reduced mobility of a limb.

**Table 1**

**Qualitative studies**

| Authors and date        | n  | Patient group   |
|-------------------------|----|---|
| Woods M, 1993           | 37 | Women with breast cancer treatment-related arm lymphoedema  |
| Woods M, 1995           | 40 | Women with breast cancer-related arm lymphoedema  |
| Carter BJ, 1997         | 10 | Women aged 36–75 years with breast cancer-related lymphoedema   |
| Hare M, 2000            | 20 | Women aged 48–71 years following breast/auxillary surgery/radiotherapy for breast cancer  |
| Johansson K et al, 2003 | 12 | Women with breast cancer-related lymphoedema for at least one year and who worked outside the home  |
| Ryan M et al, 2003      | 82 | Women with lymphoedema of the lower limbs following surgical and radiation treatment for gynaecological cancer  |
| Williams A, 2006        | 15 | Men and women with lymphoedema of a variety of causes, including: breast cancer; cervical cancer; carcinoma of the penis, lower limb venous insufficiency and primary lymphoedema |

In addition, a common finding is that the volume of swelling, often used as a treatment outcome is not correlated with improved HRQoL. Equally, these

studies indicate that adjustment to lymphoedema can be adversely affected by low levels of perceived social support and the use of an avoidant

**Table 2**

**Cross-sectional studies**

| Authors and date                | n   | Patient group   | Conclusions  |
|---------------------------------|-----|---|--|
| Tobin MB et al, 1993            | 50  | Women with breast cancer lymphoedema                                  | Patients with arm swelling experience greater functional impairment, poorer psychological adjustment and increased anxiety and depression                |
| Beaulac SM et al, 2002          | 151 | Women with surgically treated early stage breast cancer               | Impact of lymphoedema on long-term quality of life is appreciable and should not be underestimated   |
| Pereira de Godoy JM et al, 2002 | 23  | Comparison of patients with and without lymphoedema                   | HRQoL of patients with lymphoedema is poorer than in patients without lymphoedema, particularly in ability to function physically, mentally and socially |
| Moffatt CJ et al, 2003          | 228 | Comparison of patients with lymphoedema with published normative data | Poorer HRQoL in patients with lymphoedema compared with normative controls, particularly in ability to function physically, socially and emotionally     |

Table 3

## Longitudinal studies

| Authors and date                   | n   | Patient group  | Conclusions  |
|------------------------------------|-----|--|--|
| Mirolo BR et al, 1995              | 25  | Women with breast cancer treatment related arm lymphoedema evaluated pre-intensive versus post-intensive treatment and followed up at 6 and 12 months  | A combination of intensive treatment and education for self-management can reduce swelling and improve HRQoL   |
| Passik SD et al, 1995              | 69  | Women with arm lymphoedema seeking rehabilitation following breast cancer treatment. Patients were evaluated on referral to rehabilitation unit.   | Patients may benefit from psychological therapy in addition to physical rehabilitation. Assessment for pain, social support and coping styles beneficial, as was patient support group             |
| Kirshbaum M, 1996                  | 16  | Women attending a breast unit following breast cancer treatment. Cohort evaluated before and after implementation of clinical guidelines for the management of breast cancer related lymphoedema         | The development and effective implementation of research-based, patient centred clinical guidelines is important to achieving optimum HRQoL  |
| Sitzia J and Sobrido L, 1997       | 34  | Patients with unilateral or bilateral chronic oedema of upper and lower limbs attending nurse managed lymphoedema clinic. Evaluated pre- versus post-treatment with conservative treatment regime        | Significant improvement in energy, pain and physical mobility. Change in limb volume not associated with change in HRQoL. Significant correlation between skin improvement and improvement in pain |
| Velanovich V and Szymanski W, 1999 | 101 | Patients following surgery for breast cancer, divided into three groups:<br>1. Surgery without axillary lymph node dissection (ALND)<br>2. With ALND and no lymphoedema<br>3. With ALND with lymphoedema | Selective ALND or sentinel lymph node biopsy could reduce incidence of lymphoedema   |
| Weiss JM and Spray BJ, 2002        | 54  | Patients with lymphoedema of various causes. Evaluated pre- and post-treatment with complete decongestive therapy (CDT)  | Significantly greater improvement in HRQoL scores for patients with lower lymphoedema. No correlation between oedema volume reduction and post-treatment HRQoL improvements                        |
| McPherson T, 2003                  | 54  | Patients with lower limb lymphoedema secondary to lymphatic filariasis in Guyana. Comparison of disease severity with DLQI score   | Patients with higher disease severity (Dreyer score) had a higher DLQI score. increased number of cellulitis cases correlated with increased DLQI score  |
| McPherson T and Penzer R, 2003     | 11  | Patients with lower limb lymphoedema secondary to lymphatic filariasis in Guyana. Cohort evaluated pre versus post introduction of nurse-led hygiene, skin care and education regimen                    | A nurse-led service combined with patient education in community's endemic for LF is an effective intervention for improving HRQoL for patients with lymphoedema                                   |

copied style. Poor social support and avoidant coping are associated with a negative impact on body image and the reporting of significantly greater pain.

### Conclusion

This review has a number of implications for practice. It draws

attention to the need for clear, timely and ongoing information and support that is readily available to both patients and their carers. It points to the need for education programmes for patients, their carers and healthcare professionals and for accessible focused specialist

services. Finally, the primary aim of treatment must be to improve and maintain the patient's HRQoL. If this is to be achieved, the evidence from this review points to the importance of having in place a coordinated approach to treatment and management that is based on an

integrated, evidence-based framework of care. Clearly, the HRQoL of patients with lymphoedema is a key outcome when evaluating the success of such approaches. JL

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## Key points

- ▶▶ This brief paper reviews the health-related quality of life (HRQoL) literature in order to assess the impact of lymphoedema on the lives of patients.
- ▶▶ The search results were categorised into three broad areas, namely: qualitative research, cross-sectional studies, and longitudinal and outcome studies.
- ▶▶ This review draws attention to the need for clear, timely and ongoing information and support that is readily available to both patients and their carers. It points to the need for education programmes for patients, their carers and healthcare professionals and for accessible focused specialist services.
- ▶▶ The primary aim of treatment must be to improve and maintain the patient's HRQoL.

# INTERNATIONAL DEVELOPMENT OF THE LYMPHOEDEMA FRAMEWORK

CJ Moffatt

The International Lymphoedema Framework (ILF) project aims to develop and evaluate appropriate healthcare services for patients with all forms of lymphoedema in countries throughout the world. It does this by employing a collaborative partnership approach not only with each key partner country, but also with key groups already involved in the field, including the World Health Organization (WHO), Global Alliance to Eliminate Lymphatic Filariasis (GAELF), international and national lymphology and patient support groups.

## Key words

International Lymphoedema Framework (ILF)  
Best Practice  
Partnership approach

The aim of the international lymphoedema framework is through a partnership approach to develop and evaluate appropriate healthcare services for patients with all forms of lymphoedema in countries throughout the world.

This work builds on the lymphoedema framework established in the UK. This project involves a partnership with expert clinicians and researchers, organisations, patient support groups and industry and has developed a national research project involving the implementation of an internationally agreed standard of best practice within different service models. The work has led to the adoption of a new classification of lymphoedema through the Department of Health

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(DoH) drug tariff allowing access through prescription to all products required for treatment. The common research evaluation will provide a comprehensive evaluation of the size and complexity of the healthcare problem and the clinical, psychosocial and economic benefits of adopting best practice.

The research methods used in the UK project will be adapted for the international research programme

**The overall aim of the project is to engage countries in the development of national frameworks to develop appropriate service models.**

and will involve, through international collaboration, the development of a global electronic dataset for all participating countries. The UK project is already supported by an eminent international advisory board that will continue to play a prominent role and additional expert panels and working groups will be developed to support the work of the International Lymphoedema Framework (ILF) project (Figure 1).

Effective partnerships will be required with key agencies and organisations involved in lymphoedema world-wide. These will include key groups already involved in this field, including:

- ▶ World Health Organization (WHO)
- ▶ Global Alliance to Eliminate Lymphatic Filariasis (GAELF)
- ▶ International and national lymphology groups
- ▶ Patient support groups.

## Country participation in the ILF project

The overall aim of the project is to engage countries in the development of national frameworks to develop appropriate service models. Over the next two years this work will be piloted in India, France, Portugal and Japan. Each country will be managed by a project manager who will assist the relevant organisations in undertaking the research and developing the profile of lymphoedema within the country. Additional support will be required to work where needed with relevant reimbursement agencies to ensure that high quality products are available for care. Each country will be required to ensure that the views of patients are appropriately integrated and the development of patient support groups will be actively encouraged, as their role is critical to the success of this work.

It is recognised that this project will involve a rolling programme of development. All countries will be encouraged to be involved at different levels according to their ability to develop services and undertake the research evaluation. Country membership will be open to all, allowing access to materials from the framework, including:

- ▶ *Journal of Lymphoedema (JOL)*
- ▶ Templates for practice
- ▶ Templates for management
- ▶ Educational materials.

The ILF is keen to encourage participation from less wealthy countries. Every effort will be made to provide travel resources and funds to support these countries and allow full participation in the annual conference and to assist in service development.

### Annual international conference

A major vehicle for the project will be an annual international conference. The first will be held in Ascot, UK in April 2009. From then, the conference will move yearly to different countries who are participating in the project and a joint conference will be held.

The conference will be highly interactive, involving participation of all delegates including industry partners and patients. Video linkage with countries is being considered, particularly from developing countries. In addition to the interactive sessions, some space and time for traditional presentation of research papers and posters emerging from the collaborations will be included.

During the conference the working groups and expert panels will meet. Of particular importance is the dialogue between western and eastern approaches to lymphoedema care and problem-solving of global issues such as eradication of infection.

During the conference research grants and fellowships will be awarded. These will be peer-reviewed by an international scientific panel and awarded on merit. It is hoped that dedicated fellowships will be available for those working in poorer countries. Awards of excellence will also be given.

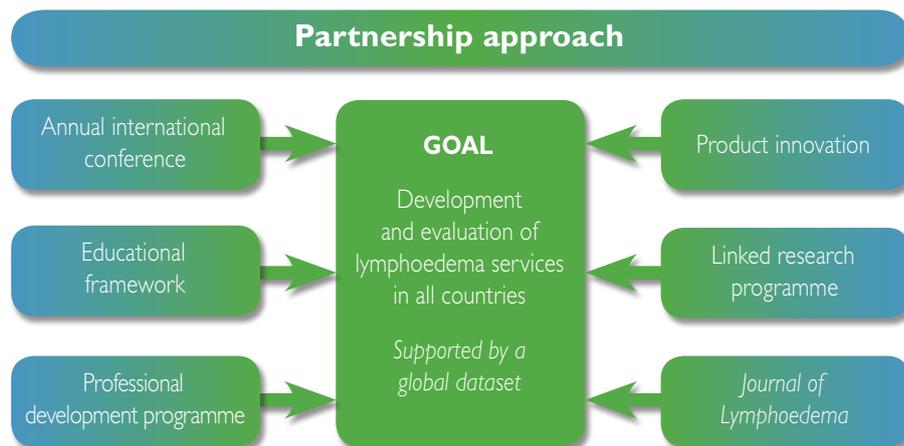


Figure 1. Key elements of the International Lymphoedema Framework.

It is hoped that the conference will also host a patient conference under the direction of the patient support groups. This will allow for patients to meet together and a dedicated programme of interest delivered. Patients and their families will be given free delegate membership and access to professional sessions.

At each conference new Templates for Management and Templates for Practice will be launched. Opportunities for exhibition and symposia will be available.

### Journal of Lymphoedema (JOL)

The *Journal of Lymphoedema* will form the key communication channel for the ILF. The templates will form supplements within the journal and other dedicated supplements will also be possible. It is envisaged that the journal will be published in the main languages. The project will seek to provide free copies to those working in developing countries. While the journal is currently published twice-yearly, this may increase if there is demand. The journal is supported by an international editorial board, and application for inclusion on Medline is underway.

### Educational programme

The project will involve setting up a comprehensive educational framework. This will include the following dimensions:

- ▶ Post-doctoral research fellowships
- ▶ PhD fellowships
- ▶ Specialist modules (available

as paper-based and electronic resources).

It is hoped that these resources will be available in any language required and made available to the participating countries.

The educational work will be supported by the international advisory board and educational experts to ensure these are clinically accurate and educationally robust.

There is a substantive lack in many countries of appropriately trained specialists who have the specialist clinical and organisational skills to develop and evaluate services. The project will seek to develop a support programme for new specialists through a mentorship model. In addition, resources such as audit programmes will be available to this group.

### Innovation programme

As the field of lymphoedema develops, opportunities for product innovation will emerge. Partnerships with the industry members will foster this work and should lead to new approaches to diagnosis and treatment.

A key priority for this programme is considering the development of low-cost methods of eliminating infection at a global level. This may involve partnerships with pharmaceutical companies and the exploration of traditional remedies from eastern approaches to care. This work will be supported by specialist expert panels and working groups. 



