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# Health status of lymphatic filariasis assessed from patients using seven domains five levels (7D5L) instrument

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#### Abstract

Health status is the standardized description of health condition of individuals either normal or ill due to diseases and is presented as multidimentional profiles. In an effort to develop an indicator to assess the impact of morbidity intervention against lymphatic filariasis (LF), we assessed the health status of seven different clinical manifestations (health states) of LF from the patient's perspective. One hundred and seventy-four filarial patients either with hydrocele or lymphoedema were involved in the study. Acute episode of adenolymphangitis (ADL) among chronic patients was considered as co-morbidity. Severity levels, focusing on physical, mental and social dimensions of health were defined and quantified, using seven domains and five levels (7D5L) instrument, an extended form of EuroQol (5D3L). All the seven domains of health are affected by filarial disease, with the levels of severity varying with health states. The mean severity score of ADL (25.8) was significantly higher compared to lymphoedema (10.7) and hydrocele (6.9) (P < 0.05). In males, the mean score of lymphoedema (11.6) was significantly higher in comparison to hydrocele (P < 0.05). The severity scores increase with the progression of filarial disease but independent of gender. The health states of LF were further classified based on the percentage of severity according to International Classification of Functioning, Disability and Health (ICF) on impairments. Lymphoedema grade 4 (oedema with skin changes) and ADL were ranked as severe. The importance of these findings is discussed in view of priority setting and evaluating the morbidity management under Global Programme for Elimination of Lymphatic Filariasis (GPELF).

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Keywords: Lymphatic filariasis; Burden; Instrument and severity levels; Health status; Health domains; Morbidity management; Elimination

## 1. Introduction

Health status (HS) is the standardized description of health state of an individual either normal or ill due to disease (Andresen et al., 1998). The description can be presented as multidimensional profiles of health (WHO, 2003) based on a variety of domains reflecting physical,

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mental and social outcomes of a health state. Health status provides additional information on illness or wellness and is often measured from the individual's perspective. These measures are primarily used for measuring the ability of an individual to perform activities required in daily life. An individual can be considered disabled, though varying in degrees when an activity is limited in its nature, duration, or quality of performance (Michelle and Ralph, 2000). A change in HS is often the only or the first sign of an illness or exacerbation of an existing illness. Recently, the International Classification of Functioning, Disability and Health (ICF) has designed a multipurpose classification for describing health states

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to improve communication between different users like health care workers, researchers, policy makers and community including persons with disability (WHO, 2001a). Self-reported health status is also receiving increasing attention in epidemiological and outcomes research (Andresen et al., 1999).

Lymphatic filariasis (LF) caused by filarial parasites remains an important public health problem in at least 83 countries worldwide with about 120 million people affected (WHO, 2004). This tropical disease manifesting as different health states causes long-term suffering and morbidity as well as high social and economic burden to individuals and communities (Gyapong et al., 1996; Dreyer et al., 1997; Ramaiah et al., 1997, 2000). It also imposes burden on the health care infrastructure in endemic areas (Haddix and Kestler, 2000). Even though the disease does not kill, it is ranked as the second leading cause of disability (WHO, 1995; Durrheim et al., 2004). However, its control has not attracted the adequate attention of the health policy makers (Evans et al., 1993). With dramatic advancement in research towards the development of tools and strategies, now this disease has been rated as eradicable one. Global Programme for the Elimination of Lymphatic Filariasis (GPELF), launched in 2000, is proposed to cover 350 million people in 46 countries in 2005 (Ottesen et al., 2004). To facilitate this effort of upscaling, it is necessary to strengthen activities at different levels. Advocacy is considered as an important component to ensure programme implementation. Information on the burden due to LF is crucial for advocacy. Till recently there was a general lack of information on the functional status of LF patients and the levels of disability and sufferings due to the acute and other stages of the disease. As a result, the estimates of the impact of the disease were largely underestimates (Gyapong et al., 2000). Also, it is essential to understand the severity of disability due to LF in the physical, mental and social health to implement morbidity management programme which is an important component of GPELF (WHO, 2001b). In this communication, we attempted to address the critically important but frequently overlooked aspect of the severity of burden due to different health states of LF and to develop indicators to assess the impact of efforts to reduce LF related disability in those already affected with chronic manifestations of the disease.

#### 2. Material and methods

## 2.1. Study area and cases

The study was carried out in Pondicherry urban agglomeration and two LF endemic villages in Villupu-

ram District of Tamil Nadu state in south India. There were 212 patients, detected through physical examination by the health worker through house visits as well as those who reported at the Filaria Night clinic at Pondicherry. A total of 174 patients between 15 and 60 years of age were involved in the study. The patients were classified into different health states (clinical manifestations) following WHO classification criteria (WHO, 1992). Acute attack of adenolymphangitis (ADL) among the chronic patients was considered as co-morbidity and treated as a separate health state. Patients either suffering from the attack of ADL at the time of interview or had the history of attack were recruited for assessing the effect of ADL. A recall period of 30 days was considered as ideal so that the patient could recollect the sufferings experienced due to ADL. No time frame was assigned to chronic cases of LF as the manifestations and symptoms are irreversible, inflicting persisting health effects even when they are under clinical management. But episodes of ADL are recurring and the symptoms are of temporary nature and each episode has a short duration of 4–5 days. This was considered as the time frame for ADL though the effect on domains like anxiety and depression is likely to remain for a longer period because of sufferings and the fear of getting the ADL attacks again.

#### 2.2. Health states

Based on the criteria recommended by the World Health Organization (WHO, 1992), six chronic manifestations of lymphatic filariasis namely lymphoedema grade 1 (L1: pitting oedema of the limb that is reversible on elevating the limb), lymphoedema grade 2 (L2: pitting/non-pitting oedema that is not reversible on elevation of the limb and the skin is normal), lymphoedema grade 3 (L3: non-pitting oedema of the limb, not reversible on elevation and the skin is thickened), lymphoedema grade 4 (L4: non-pitting oedema with fibrotic and verrucous skin changes), hydrocele grade 1 (H1: <15 cm diameter) and hydrocele grade 2 (H2: ≥15 cm diameter) and acute episodes of adenolymphangitis (ADL: recurrent attacks of fever associated with inflammations of the lymph nodes and/or lymph vessels) associated with chronic manifestation were considered as health states of LF.

## 2.3. Instrument used for measuring HS

A seven domains and five levels (7D5L) descriptive instrument was used to assess the health status of filariasis. Description of severity levels and domains are given in Table 1. The Standard European Qual-

Table 1
Description of health domains and respective severity levels

Domains	Levels				
	No problem (1)	Mild problem (2)	Moderate problem (3)	Severe problem (4)	Extreme problem (5)
Mobility: The ability to walk, move around, move around in different locations, move around using transportation, etc.	No problems in mobility	Mobility not restricted but difficult	Mobility restricted without help	Mobility restricted, with help (walking aid/person)	Not able to walk or move
Self care: The ability to walk, move around, move around in different locations, move around using transportation, etc.	No problems in caring self	Difficulty in taking care of self	Only very essential needs of self are met	Require some one to help for care	Unable to take care of self
Usual activity: The ability to do professional work/household work like shopping, cooking, taking care of children and sick members of the family, repairing, painting, maintaining, etc.	No problems in performing usual activities	All usual activities performed with difficulty	All usual activities restricted	Only very essential activities performed that too with help	No activities at all
Pain/discomfort: Localized/generalized pain and aches and discomforts like breathlessness, burning sensation, etc.	No pain/discomfort	Mild pain/discomfort that did not interfere with routine activities	Compelled to take rest because of pain/discomfort	Self treatment with drugs	Consult a doctor and need total rest
Anxiety/depression: Mental distresses like feeling sad and depressed, feeling nervous and in low spirits, loose interest in most things as hobbies, personal relationships, etc.	No anxiety/depression	Does not interfere with performance	Leads to low performance/irritating tendency	No performance, total detachment and isolation	Suicidal tendency
Cognition: The ability to memorize, learn concentrate and comprehend.	No cognitive problem	Reduced concentration/memory, performance not affected	Reduced concentration/memory, performance affected	Loss of concentration/memory, no performance	Total loss of memory
Social participation: The ability to maintain social relationships, visit relatives and friends, attend//host social functions, etc.	No problem in social participation	Hesitation in involving in social activities	Restricted social activities	Avoid social activities as far as possible	Total avoidance of social activities

ity of Life (EQ-5D) instrument (Euroqol Group, 1990) was modified by incorporating two more domains and increasing the number of severity levels from 3 to 5. The seven domains include mobility, self-care, usual activity and pain/discomfort (physical), anxiety/depression and cognition (mental) and social participation (social) based on the effect of the disease on different aspects of health. The questions posed to the respondents in the domain of mobility included whether the patient was able to walk, move around in different locations, move around using transportation, drive, etc. Questions related to self-care were whether washing oneself, caring body parts, toileting, dressing, eating, drinking and looking after ones health was possible or not. Whether the patient was able to work, do services like shopping, care for household articles and take care of children and sick members of the family were the questions asked to assess the effect on usual activities. Pain or discomfort considered the questions related to the experience of localized and generalized pain. Mental health was assessed in terms of anxiety/depression and cognition. To assess the mental effect of anxiety/depression, questions related to depressed feeling, feeling negative about one self, loosing interest in most things such as hobbies, personal relationships, problems in getting sleep, etc. were posed. Cognition was valued based on whether the patient was able to memorize and learn, do activity, concentrate, comprehend, etc. The effect on social participation was assessed based on questions whether the patient was able to maintain social relationships, visit/invite relatives and friends, attend/host social functions, etc.

The degree of severity was assessed with a five point scale that ranged from no difficulty to profound difficulty experienced by the patient in each of the domains. The severity level "no problem" in physical domains is defined as a condition that indicates absolutely no difficulty in walking, caring self, performing activities and no pain. In the mental domain it is meant, no anxiety and depression or cognitive problem at all. In the domain of social participation there is no difficulty in attending/hosting social functions, maintaining social relationships, etc. "Mild" severity in the physical domains is defined as, having difficulty in walking, self-care, and performance of usual activities. Pain is defined as mild when the pain is bearable and does not interfere with routine activities. Mild severity in mental domains is meant when the feelings of anxiety and depression are experienced occasionally and have least influence on concentration. In the social participation domain, mild severity means individuals involve in social activities, but with hesitation.

Severity is ranked as "Moderate" when restricted performance is experienced in all the physical domains and no assistance is required. Pain is defined as moderate when it is manageable with some remedies. In the mental domains, it means experiencing anxiety and depression less frequently and reduced concentration causing some difficulties in performing routine activities. In the social participation domain moderate severity means that social participation is restricted. A rating of "Severe" indicates that assistance is required to perform even restricted walking, self-care and essential activities; medical consultancy is required for pain; more frequency of experiencing anxiety, depression, cognitive problems and maximum avoidance of social activities. "Extreme" severity means inability to perform anything, hospitalization for pain, extreme anxiety and depression leading to suicidal tendencies, total loss of memory, concentration or comprehension and total avoidance of social participation. Based on the above domains and severity levels a matrix was prepared and used for recording the response from the patients.

The instrument was pre-tested. The interview was conducted in the patient's domestic settings after briefing them the purpose of the interview. Informed written consent was obtained from each respondent before the interview. Confidentiality was maintained for the data obtained as per ethical guidelines (Indian Council of Medical Research, 2000). Each patient was asked to state the level of severity in each of the seven domains based on the predefined condition. The severity level of each domain was transformed into score by giving values for no problem as 0 and for mild, moderate, severe and extreme severe problem as 1, 2, 3 and 4, respectively. The values were computerized for further analysis.

## 2.4. Data analysis

The mean score of severity was calculated for each domain (domain score, ranging from 0 to 4) for a given health state. Individual scores of all the seven domains were added up to get the overall severity score (HS score) for each health state. This would range from a possible minimum score of 0 (no problem in all domains) and maximum of 28 (extreme severe problem in all domains).

The percentage of HS score of severity of each health state was calculated by using the formula:

$$\left(\frac{\text{mean HS score}}{\text{maximum expected score (28)}}\right) \times 100$$

The health states were then classified into five categories according to ICF classification of impairments (problem in body function or structure as a significant

Table 2 Number of patient-respondents participated in the assessment of health status of lymphatic filariasis

Health state	Number of patient-respondents	Median age (range) in years
Adenolymphangitis (ADL)	24	43 (18–57)
Lymphoedema grade 1 (L1)	26	45 (18-60)
Lymphoedema grade 2 (L2)	31	50 (20-60)
Lymphoedema grade 3 (L3)	23	42 (22-60)
Lymphoedema grade 4 (L4)	20	45 (20-56)
Hydrocele grade 1 (H1)	27	37 (15-59)
Hydrocele grade 2 (H2)	23	43 (33–60)

deviation or loss) and difficulty in participation (problem in involving in a life situation). The categories include no impairment (0–4%), mild (5–24%), moderate (25–49%), severe (50–95%) and complete/total (96–100%) (WHO, 2001a). Non-parametric Mann–Whitney *U*-test was used to compare the mean scores of severity.

#### 3. Results

The study group comprised of 174 patients with 90 males and 84 females affected with different clinical manifestations (health states) of LF. The number of respondents in relation to health state and gender, and median age are shown in Table 2. Episodes of acute attack of ADL were reported by 24 patients with different chronic manifestation. The median age of male patients with lymphoedema and hydrocele was 45 and 42 years, respectively. The median age of female patients with lymphoedema was 45 years.

The mean severity score in relation to health domains (Domain score-ranges from 0 to 4) of each health state of LF is shown in Table 3. Analysis of data showed that LF affects all the seven health domains and the severity scores of each domain varies with the health states. Usual activities were the most affected domain in all the health

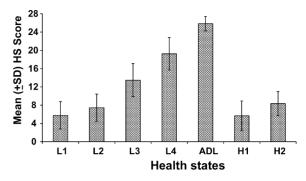


Fig. 1. Health status (HS) score (mean+S.D.) for different health states of LF.

states of LF followed by anxiety/depression. Self-care and cognition were the least affected domains. Participation in social functions was also limited. The severity score of each of the domains increase with grades (progression) of lymphoedema and hydrocele.

Among the different health states, highest severity score was assigned to ADL, ranging from 3 to 4.0 in all the domains. This was followed by L4 (domain score ranging from 2 to 3). ADL and L4 recorded maximum score for social participation. While ADL makes the patients incapacitated and prevents them from participating in functions, L4 with swollen limb, associated with or without ulceration and foul odour of the discharge makes the patient to avoid social activities.

Comparison of mean HS score (severity score on the scale of 0–28) between the health states showed ADL recorded the highest score of 25.8, followed by L4 (Fig. 1). Variability between the patients was minimal with ADL when compared with other health states. The mean HS score showed an increasing trend with the progression of lymphoedema as well as hydrocele. The HS score of lymphoedema (10.7) was significantly (P<0.05) higher than that of hydrocele (6.9) among males. The HS score did not differ significantly between male (11.6) and female (10.4) lymphoedema patients as well as patients with ADL (25.3 for male and 26.3 for

Table 3 Health states of LF and mean score of severity (on a scale of 0–4) in relation to health domains

Health states	Health domains							
	Mobility	Self-care	Usual activities	Pain	Anxiety/depression	Cognition	Social participation	
Adenolymphangitis (ADL)	4.00	3.67	4.00	3.71	3.50	3.04	3.92	
Lymphoedema grade 1 (L1)	1.19	0.23	1.20	0.88	1.00	0.54	0.69	
Lymphoedema grade 2 (L2)	1.39	0.77	1.20	1.03	1.26	0.84	0.97	
Lymphoedema grade 3 (L3)	1.87	1.52	2.22	1.96	1.91	1.74	2.26	
Lymphoedema grade 4 (L4)	2.45	2.15	3.20	2.80	2.90	2.55	3.20	
Hydrocele grade 1 (H1)	0.70	0.30	1.22	0.78	1.30	0.48	0.89	
Hydrocele grade 2 (H2)	1.43	0.35	1.78	0.83	1.83	0.65	1.48	

female) (P > 0.05), indicating that the severity was similar and the level of illness were comparable between the genders.

The overall impairment and difficulty for each health state based on the HS score of severity showed that L1 (21%) and H1 (20%) were mild, L2 (27%), H2 (30%) and L3 (48%) were moderate, L4 (69%) and ADL (92%) were severe.

## 4. Discussion

Lymphatic filariasis is known to reduce/impair the physical functioning of the patients (Ramaiah et al., 1997). In the present study, we further quantified the level of deterioration in functional status of individuals with filarial disease in terms of severity. All seven health domains are affected. ADL, an acute health state is of short duration and transient in nature, but recurring among the chronic cases of LF. It recorded the highest severity levels in all the domains. This health state can cripple the affected individual up to 5 days (Ramaiah et al., 2000). They remain physically incapacitated due to pain, lymphadenitis, lymphangitis, and inflammation of the part of the limb/scrotum involved (Krishnamoorthy, 1999). Fever associated with chills and systemic manifestations such as nausea, vomiting, and loss of appetite confine the patient in this health state to bed for 3-5 days (WHO, 1984). ADL imposes very severe problems in mobility, self-care, and usual activity and the patients had to endure very severe pain, which affected their mental health in the form of very severe anxiety/depression and cognitive problems. The severity in the domains of physical and mental health influenced the domain of social participation and the variability between the patients is minimal. In majority of chronic cases, ADL episode is repeated and hence considered as co-morbidity. The proportion of patients experiencing ADL was higher among lymphoedema compared to hydrocele and among lymphoedema patients, the number of episodes and the duration of the episodes increase with the progression of the disease (Pani et al., 1995). When ADL is associated with chronic manifestations as co-morbidity, the severity level of all the chronic cases gets enhanced.

Acute episodes of local inflammation involving skin, lymph nodes, and lymphatic vessels associated with chronic manifestation of LF are mostly the results of bacterial infection of the skin with entry lesions. Careful cleaning can be extremely helpful in healing the infected surface area and in both slowing and even more remarkably reversing much of the overt damage that has occurred already. Management of morbidity associ-

ated with LF, primarily lymphoedema and hydrocele is an important feature of global programme to eliminate LF (WHO, 2001b). Measures of disability prevention related to managing, treating, or alleviating filarial disease includes basic hygiene and skin care to prevent ADL attacks and reduce the risk of lymphoedema progression. This approach is appropriate as the patients are compelled to seek medical intervention mostly when they get ADL. Further, the present study shows that patients perceive ADL as the major concern affecting all the domains of health.

Among the chronic cases in males, lymphoedema had higher severity than hydrocele. This is because of the skin lesions associated with lymphoedema exposed to the risk of getting secondary infections. This further contributes to the pre-existing lymphatic damage (Burri et al., 1996). Among the lymphoedema and hydrocele patients, the severity increases with the advancement in disease progression. Classification of health states based on overall impairment and difficulty in social participation showed that ADL and lymphoedema grade 4 impose severe problems, indicating that measures to target patients with advanced clinical progression associated with ADL need to be prioritized. The severity scores of ADL and lymphoedema do not vary between genders, necessitating equal attention to both the genders for promoting practice of home management methods. As a long-term measure of disability prevention, surgical correction needs to be promoted for hydocele.

The instrument developed in the present study can be a tool for assessing the impact of morbidity management programmes either at individual or community level. Functional health status will help in evaluation and audit of health care by measuring changes in health status in individual patients, assessing the seriousness of conditions at different moments in time. The present findings on severity levels varying between health states of lymphatic filariasis indicate the need for morbidity management package including measures specific to the health state. As a tertiary prevention measure, counseling of patients should also be included as the patients experience anxiety/depression and problems in social participation as well.

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