

TREATING LYMPHOEDEMA PATIENTS IN INDIAN VILLAGES

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In 2004, the Institute of Applied Dermatology (IAD) developed an integrated treatment programme for lymphatic filariasis (LF) for rural communities. This included a combination of treatment elements from allopathy, Ayurveda and yoga therapy, to deliver low cost, home-based, self-care treatment with the support of a family member. Patients were treated at the outpatient department in Kasaragod, and two peripheral community units were set up in 2010. Mass camps were also conducted in three endemic districts of Kerala. The projects are nearing completion. This paper gives an overview of these programmes.

Key words

Ayurveda
Integrative treatment
Morbidity control
Community-based
rehabilitation

In 2004, the Institute of Applied Dermatology (IAD) developed a low-cost integrative treatment protocol for lower limb lymphoedema. Treatment consists of a combination of compression bandaging, skin care, herbal-based procedures of traditional Indian medicine (Ayurveda), and yoga exercises (Narahari et al, 2007). Lymphoedema in India is mainly due to lymphatic filariasis (LF), a mosquito-borne disease caused by the parasite *Wuchereria bancrofti* (Cobbold, 1877). These parasites reside in the lymphatics and enter into lymph nodes, developing into adult worms which destroy the lymphatic system. Lymph then gradually accumulates in tissue spaces and lymphoedema occurs. India has 7.44 million lymphoedema patients

caused by LF alone (Michael et al, 1996; Ramaiah et al, 2000), and there are 470 million people at risk (<http://nvbdcp.gov.in/fil5.html>). In addition, secondary

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lymphoedema due to cancer and primary lymphoedema contribute to the pool of lymphoedema patients.

Until November 2011, 964 patients (1315 limbs) have been treated with the IAD protocol. This involves treatment and medicine from Ayurveda, breathing exercises and yoga, long-stretch compression bandaging and care of entry points using biomedical drugs. There is a dedicated outpatient department to manage lymphoedema patients who come from all over India. Most patients are referred, or get information from the net or media reports. There are two full-time counsellors and one nurse counsellor. During baseline counselling sessions, close family members are encouraged to participate. Treatment procedures as well as before and after treatment photographs of both patients who comply and those who do not are shown. As most patients in India are not covered by insurance, they are informed

of the estimated cost of treatment (333–555\$). Although this is low cost for middle and upper class Indians, it continues to remain above the reach of the average LF patient in India.

Following baseline counselling, those registered for treatment are given the option to opt out during admission counselling. In all counselling sessions, the need for lifelong commitment to the integrative treatment is stressed. Treatment workshops cover the training of family members to provide assisted, home-based care. Six to eight patients are admitted for each workshop, which lasts for two weeks. Initially, nine days of treatment procedures are performed by the therapists as patients' carers observe. During the last five days, the family member is trained to perform all procedures. Yoga is taught step by step, initially supported by a yoga therapist and later patients are encouraged to do it for themselves. This treatment workshop is supervised at all three levels: a junior doctor is a member of the treatment team, a postgraduate Ayurvedic doctor conducts daily rounds, and the author does weekly rounds. A 40-page case sheet helps to monitor minute details. At the community health centre level, patients are managed by a team lead by an undergraduate Ayurvedic doctor and an allopathic nurse.

Involvement of a family member helps to reduce stigma and improves

compliance (Narahari and Ryan, 2011), although the author and his team are increasingly identifying nuclear families in villages in many endemic clusters, where more than one member of the family are affected by the disease. Patients learn during the treatment and training is reinforced daily by the counsellor. In addition, patients are asked to attend classes on skin care, Indian manual lymphatic drainage (IMLD), compression, entry points and patient education. Group discussion is held weekly with the junior doctor and patients. This helps to reinforce what they have learnt and to address any unanswered questions.

Patients are followed up after one month and then three months later, where the counsellor advises on any deficiencies in home-based care, such as improper breathing coordination, yoga exercises and faulty compression techniques. Therapists who examine follow-up patients base their teaching on the counsellor's notes. Response to treatment is assessed using SPSS software 16. Figure 1 shows the follow-up of a patient after six years.

SPSS 16 classified data revealed a total of 1315 limbs with 868 limbs classified as small, 380 limbs as large. 8.7 litres was the dividing value for large and small limbs. Entry points were present in 1061 (86.5%) limbs at baseline and in 463 (72.3%) limbs after 104 days' treatment ($p < 0.01$). The number of limbs suffering inflammatory episodes significantly reduced from 84.8% at baseline to just 8.6% by the 104th follow-up day ($p < 0.01$), as a result of treatment. After three months' treatment volume reduction for large limbs was 5.3 litres (43.3%), with a confidence interval (CI) of 4.9–5.9 litres ($p < 0.01$), and 1.4 litres (24.7%) for small limbs with a CI of 1.3 to 1.5 litres.

Focus of infection (entry points) was present in 86% at baseline and reduced to 71% by three months. The presence of entry points poses the risk of getting another inflammatory episode. Hence, counsellors continue to educate patients by telephone on entry points.

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planningcommission.nic.in/plans/planrel/fiveyr/11th/11_v2/11th_vol2.pdf). LF affects the poorest of the poor and India is the home for a third of the world's affected patients. A recent publication of the World Health Organization (WHO) states that IAD is one of the leading lymphoedema clinics in the world (Macdonald and Ryan, 2010). Being in India, the author's clinic have to meet the needs of the poor who cannot afford the charges. Therefore, the author and his team regularly raise sponsorship from philanthropists. To date, sponsorship has been raised to treat 220 poor patients. Support in kind is also given, i.e. short-stretch bandages, mainly by Gerben Schrale, a physiotherapist from the Netherlands.

As such sponsorship is unable to meet the growing list of poor patients waiting to follow this

treatment regimen, the author has approached the department of AYUSH, Government of India, for grants. In August 2010, IAD received a grant of 20 million Indian rupees to provide free treatment to 500 patients in each of two endemic districts of south India: Alleppy in Kerala and Gulbarga in Karnataka. This project is a public private partnership scheme and aims to treat poor LF patients from villages (Figure 2). The treatment units are being established utilising the infrastructure of local community health centres. In addition, the project has an objective to prove that integrative, family member-assisted and home-based treatment can be implemented in remote villages supported by telemedicine.

New recruits are trained at IAD for one week to become lymphoedema therapists. The author's team has developed training modules that include theory and practice. A telemedicine unit is established at IAD to monitor and guide treatment. In the author's opinion, this is the first morbidity control programme implemented in rural endemic pockets, using locally available and culturally acceptable treatment that is self-care and home-based. This pilot project is for 18 months.

Quality of life

Fifteen per cent of India's LF patients live in Kerala; but prevalence is also high in the districts of Kasaragod, Calicut and Alleppey. Under a grant from the Environment Management Agency of Kerala, the author and his team began to assess quality of life (QoL) of LF patients in these districts. Data available in the district medical office helped to identify two primary health centres serving most endemic pockets. Primary stakeholders are reached through secondary stakeholders such as



Figure 1. A 17-year-old patient followed for six years following two weeks of supervised treatment training. The patient is continuing self-care treatment at home. Pictures show the gradual reduction in limb size.

Asha workers (accredited social health activists — the National Rural Health Mission has provided every village in India with a trained female community health activist). Asha workers generally know houses in their villages which have LF, and motivate LF patients to attend the author's camps.

Mass contact camps are conducted at these primary healthcare levels, with attendance of around 20–30 LF patients. During these camps, baseline information on QoL is recorded, such as self-care, physical ability, psychological and social issues. Quality of life questions are developed on the basis of the Vector Control Research Centre model (Krishnamoorthy et al, 2008). Patients attending these camps are given one day of practical training on washing with soap and water, and yoga exercises (Figure 3). To improve understanding, patient education materials are distributed.

Quality of life has improved in those patients who followed the instructions received in the camps. 4.6% of patients who had their mobility severely affected before attending the camp, felt that it had improved considerably afterwards.

The aim of these two projects was to determine the effectiveness of integrated treatment, and to reach the large number of LF patients in the community and raise awareness of treatment options. The project treated 600 patients in Malkhaid of Gulbarga district in Karnataka province. This included 52 large limbs and 602 small limbs. In Cherthala of Alleppey district of Kerala, the project treated 400 patients. This included 111 large limbs and 387 small limbs.

A schoolchildren's survey of Kasaragod town is currently underway to determine lymphoedema prevalence. A total of 706 students have participated in the survey. Of the 11 (1.5%) students who indicated positively for lymphoedema in the questionnaire, after examination, clinical lymphoedema was detected in three students (0.4%).

A lymphoedema education



Figure 2. Dr GK Swamy from National Ayurveda Research Institute for Vector Borne Diseases examining a patient who is practicing home-based self-care integrated treatment at Cherthala, Alleppey district of Kerala province. His institute funded the community-based morbidity reduction programme being implemented in two districts of south India.



Figure 3. Yoga teaching at community as part of QoL project.

programme to nursing students in five nursing colleges is also being conducted. In addition, the author and his team regularly conduct similar programmes to local nursing students. In general, whenever lymphoedema therapists or volunteers visit IAD, they share experience with local nursing students. The author's team is fortunate to get such volunteers from Europe and USA. Their visits help to exchange knowledge

and to improve treatment methods. The author would particularly like to mention the visit of Regina Forster, a physiotherapist from Foldi's clinic, Germany. She trained staff, doctors and nurses from different parts of India, and taught abdominal lymph drainage, improved compression techniques and instructed on how to use local materials effectively. The author and his team also learnt about the use of 'chawky bags

and chawky moulds' from Avril Lunken, occupational therapist, Melbourne, Australia. These are prepared by folding small pieces of foam in a smooth cotton cloth and inserting them gently between skinfolds. They separate folds that are formed in grotesque limbs and 'dekin' the lymph flow, thereby helping to reduce limb size.

Professor Hemangi Jerajani, GS Medical College, Mumbai who is the president of the Indian Association of Dermatology, Venerology and Leprology (IADVL) has also visited IAD with the Association's secretary Professor Ramesh Bhat, Fr Muller's Medical College, Mangalore. They invited the author to apply for recognition by the IADVL fellowship programme. This enables IADVL to depute its members to learn integrative lymphoedema therapy.

Since Professor Christine Moffatt came to IAD in 2007 and 2008, partnership between the IAD and the International Lymphoedem Framework (ILF) has been well established. The proceedings of the 3rd National seminar on evidence-based and integrated medicine for lymphatic filariasis, organised by IAD at Kasaragod was published as a supplement to the *Journal of Lymphoedema (JOL 3(2)*, 2008). The ILF invited the team from IAD to the second ILF conference in Brighton, UK. IAD demonstrated yoga exercises that are taught to LF patients in a separate session. During this conference, Mr Naveen Tarur was invited to explain IAD's morbidity control programme for rural India. Dr Mwele Ntuli Malecela, the then president of the Global Alliance for the Elimination of Lymphatic Filariasis (GAELF), invited Mr Naveen Tarur to present IAD's integrative treatment during the sixth biannual conference of GAELF at Seol. Mr Tarur's travel was partly supported by the Institute of Applied Dermatology and GAELF.

The inauguration of the new building for the IAD took place on 2 December 2011, attended by Mr Nellikunnu, the local MLA, and high ranking Government officials, including the former secretary to the department of AYUSH, Mrs

Jalaja Sinha. This was followed by the fifth National Symposium on Evidence-based and Integrative Medicine for Lymphatic Filariasis and other Chronic Dermatoses, which focused on the audit of LF patients who received integrated treatment. Lymphoedema management in India is traditionally under biomedical care. Surgical treatments, nodovenous shunt and debulking operations are the lead treatment options available in most public health institutions. However, there are no long-term studies on surgical treatments, their outcomes and follow-up. They are relatively expensive and require prolonged inpatient postoperative care. The procedure would be impossible to provide for all of India's lymphoedema sufferers. Shenoy et al (1997) was the first in India to demonstrate that skin washing reduces the entry points for bacteria and, thereby, the frequency of inflammatory episodes. The national filarial control programme has now adopted this simple procedure. In most filarial treatment units, skin washing is practiced and taught to patients through local language handouts.

IAD's treatment is integrative and combines the benefit of biomedicine, Ayurveda and yoga. However, in India the provision of medical treatments is compartmentalised (Valiathan, 1990). Hence, there exists practitioner rivalry and a consequent lack of awareness of each other's systems of medicine. This ignorance of the benefit of each system of medical treatment unfortunately exists among doctors who are at the policy-making level in provincial and central government departments.

The author and his team implemented a morbidity reduction programme in the periphery at community health centre level with an Ayurvedic doctor and an allopathic nurse, supported by training from Kasaragod unit and telemedicine. They hope that the outcome of the morbidity control programme funded by AYUSH will provide more evidence to convince the biomedical health sector that priority government funding should be rolling out LF morbidity control through public and private partnership. JL

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