

FIELD EXPERIENCE OF HANDICAP INTERNATIONAL

Pierre Brantus

Even if around 180 million people suffer from lymphoedema worldwide (Casley-Smith et al, 1997), its impact as a public health problem is underestimated. The main reason for this being the lack of epidemiology. Both in developed and developing countries, the prevalence and incidence of lymphoedema is unknown. In developing countries, lymphatic filariasis (LF) is seen as the major cause of lymphoedema. The Global Programme to Eliminate Lymphatic Filariasis (GPELF) highlights the problem of lymphoedema at the international level, estimating that 16 million people suffer from lymphoedema due to LF.

Although the aetiologies of lymphoedema differ in developed and developing countries (respectively caused by surgery for breast cancer and by lymphatic filariasis), these lymphoedemas could all, theoretically, be managed by the same measures (prevention of cutaneous infections by skin care and reduction of oedema). However, due to the lack of available human and technical resources in developing countries, the management and care of patients with lymphoedema differs from that in developed countries. For example, while hygiene based on daily washing is applicable everywhere for skin care, the treatment of entry points, such as intertrigo or skin infections varies, depending on the availability of local antiseptics and antibiotics, as well as the financial capacities of the patients.

Reduction of oedema again depends on available resources. In developed countries it is possible to have recourse to massage, lymphatic drainage by healthcare professionals, techniques of binding and compression therapy with or without the patient's participation. In the majority of developing countries, only exercises carried out by the patients themselves

Although the aetiologies of lymphoedema differ in developed and developing countries (respectively caused by surgery for breast cancer and by lymphatic filariasis), these lymphoedemas could all, theoretically, be managed by the same measures (prevention of cutaneous infections by skin care and reduction of oedema).

are possible. It should be noted that certain traditional medicines and types of massage play a part in lymphoedema management (i.e. ayurvedic medicine). Kerketta et al (2005) mentioned that in the context of lymphoedema due to lymphatic filariasis, the intensive techniques for managing lymphoedema used in developed countries have been little evaluated. Conversely, Williams et al (2002) noted that clinical experiments in developed countries have shown the effect of simple lymphatic drainage carried out by the patient in the long term, either as part of combined intensive treatment or when no other help was available.

Despite the results achieved by compression bandaging, Handicap

International, based on its 25 years' experience in rehabilitation and physiotherapy, does not recommend its use for managing lymphoedema in the community in developing countries. The reasons for this are:

- ▶ Unavailability or high cost of materials
- ▶ Lack of trained staff
- ▶ Difficulty in having regular access to healthcare facilities
- ▶ Difficulty in carrying out regular patient follow-up.

The problem of regular patient follow-up is by far the most important as this can lead to unsuitable application of bandaging and incorrect lymphatic drainage by the patient, both of which can cause more harm than good. To help morbidity control, Handicap International prefers using the minimal package of measures as recommended by the World Health Organization (WHO) for lymphoedema due to lymphatic filariasis. This involves washing the entire limb carefully, paying specific attention to the hygiene of the interdigital web and wounds, elevation of the affected limb during rest, work and at night, practising simple exercises, mobilising the affected limb and wearing suitable shoes.

This minimal package of activities focuses on prevention of acute attacks, a major factor in stopping the progress of lymphoedema, rather than decreasing the volume. Pilot projects in Madagascar, Sri Lanka, Zanzibar (United Republic of Tanzania) in 2004–2005, and Haiti in 2001 demonstrated that when patients affected by chronic manifestations of lymphatic filariasis carried out daily washing of the limb, elevation and exercises with or

without assistance, this had a significant impact on the frequency of acute attacks (WHO, 2004), and on the quality of life of the patients (WHO data unpublished 2005; McPherson, 2003). From the author's personal data, in Madagascar, Sri Lanka and Zanzibar (United Republic of Tanzania), evaluation over a two-year period showed that these results had been maintained. In all these countries, individual observations have shown a decrease of the volume, especially for grades II and I (WHO staging). However, Morgan (2005) emphasised that the volume of lymphoedema does not necessarily correlate with an improvement in quality of life.

In a review of the literature, Morgan (2005) highlighted the important and negative repercussions of the impact of lymphoedema on patients' quality of life in the areas of anatomical and physiological functions, psychological effect and mobility.

In 1997, WHO (50.29) resolved that LF should be eliminated as a public health problem, which was mainly due to the chronic manifestations of the disease. Together with many international partners and especially the financial support and gifts of ivermectin and albendazole from GlaxoSmithKline and Merck, WHO established the Global Programme to Eliminate Lymphatic Filariasis (GPELF) (WHO, 2005). The second component of the strategy was the implementation of disability management activities for those already suffering from LF-related disabilities (especially lymphoedema) in order to reduce the burden of LF. The strategy, established in the specific context of resource-limited settings in LF endemic countries, focuses on simple, basic interventions managed by LF patients themselves through a community, home-based care approach. This involves:

- ▶ Patient participation in all aspects of treatment
- ▶ A community-based network for follow-up
- ▶ Using locally available resources
- ▶ Providing information/education to patients and the community.

These basic interventions for lymphoedema management provide a minimum but efficient package of activities, including skin care, exercise, elevating the affected limb and wearing suitable shoes. Each country could adapt the activities according to their available resources. When human and technical resources are available, complex physical therapy could be implemented, including manual lymphatic massage/drainage carried out by healthcare professionals and the wearing of compression garments. GPELF has highlighted the problem of lymphoedema and LF at an international level, thus providing the opportunity to use LF as an entry point for approaching lymphoedema issues in developing countries.

Handicap International works in partnership with local and national organisations at country level to provide a multidisciplinary approach to lymphoedema management encompassing clinical care, health education, counselling, socio-economic support and footwear, where needed.

In developing countries, particularly those endemic for filariasis, the diagnostic resources generally do not allow for an aetiological diagnosis to be made. Management of lymphoedema takes place regardless of the aetiology. Handicap International has carried out projects in Burkina Faso and Madagascar on disability prevention related to LF using the WHO recommendations. Based on the experiences from these projects and others on buruli ulcer and diabetes mellitus, Handicap International, in coordination with the WHO 'Global Initiative of Lymphoedema and Wound Care', is in the process of developing tools to manage, monitor and evaluate lymphoedema and chronic wounds, regardless of the cause, in limited resource settings.

Morgan et al (2005) found that the main determining factors for disabilities are the frequency of acute inflammatory episodes (AIEs), the

presence of pain, the quality of skin, a lymphoedema in a predominant member and a reduction in the mobility of the member affected. In the context of LF, Handicap International has contributed with WHO to the development of indicators for monitoring disability prevention activities, as well as the frequency of acute episodes and quality of life or level of disability of patients affected by lymphoedema. This will help to evaluate the impact of disabilities and interventions on the patient's health status, with respect to impairment and participation (WHO, 2006). JL

References

- Casley-Smith JR, Casley-Smith JR (1997) *Modern treatment for lymphoedema*. Adelaide. Lymphoedema Association of Australia
- Kerketta AS, Babu BV, Rath K, Jangid PK, Nayak AN, Kar SK (2005) A randomized clinical trial to compare the efficacy of three treatment regimens along with footcare in the morbidity management of filarial lymphoedema. *Trop Med Int Health* 10(7): 698–705
- McPherson T (2003) Impact on the quality of life of lymphoedema patients following introduction of a hygiene and skin care regimen in a Guyanese community endemic for LF: a preliminary clinical intervention study. *Filaria J* 2: 1
- Morgan PA, Moffatt CJ, Doherty DC, Franks PJ (2005) UK Lymphoedema Framework Project. *EWMA J* 5(2)
- Williams AF, Vadgama A, Franks PJ, Mortimer PS (2002) A randomized controlled crossover study of manual lymphatic drainage therapy in women with breast cancer-related lymphoedema. *Eur J Cancer Care* 11: 254–61
- World Health Organization (2001) *Innovative Care for Chronic Conditions*. Meeting report 30–31 May, 2001. WHO, Geneva
- World Health Organization (2004) Lymphatic filariasis: progress of disability prevention activities. *Wkly Epidemiol Rec* 47(79): 417–24
- World Health Organization (2005) Global programme to eliminate lymphatic filariasis. *Wkly Epidemiol Rec* 80(23): 202–12
- World Health Organization (2006) Informal consultation on preventing disability from lymphatic filariasis. *Wkly Epidemiol Rec* 40(81): 373–84