Lymphoedema management in the context of poverty alleviation

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Poverty alleviation is one of the major shared international objectives of all the United Nations agencies, such as the World Health Organization (WHO) and the World Bank, and health impairments (blindness, impairment of manual dexterity or the ability to walk), must be better managed, not least because they are a major contributor to poverty and destitution.

Lymphoedema is an impairment that causes loss of mobility, loss of manual dexterity, recurrent inflammatory episodes requiring periods away from work, and even admission to hospital. The list of cautions given out by therapists to patients with oedema advises restrictions in daily living. All this is a burden that is all the greater for the poor in countries without well-developed health and social services, especially in rural areas, for whom access to help is limited because of distance, cost and the knowledge of healthcare providers. In many cases, to receive good advice and care means travelling a great distance. Even when able to access healthcare services, most are notably limited in their knowledge of best practice in the management of lymphoedema.

Given the sheer number of people affected by lymphoedema (amounting to no less than 100 million if all causes and age groups are considered) due to filariasis, cancer and its treatment, immobility, or the chronic overload on the lymphatic system by other forms of lymphoedema, it is not surprising that the World Health Organization (WHO) rates it as one of the most important health burdens worldwide. The great majority of populations affected by lymphoedema are rural and poor, raising the issue of access to health care. For example, a family with a member suffering from swelling of the legs in a country such as Nepal may take 3–5 days to reach a hospital and, in the rainy season, flooding may prevent any access at all. After the rainy season the demands for every family member, however sick, to help with the tilling and planting in the fields will take priority.

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The plight of those living in poverty would be more easily solved if the world was not constantly under threat of, or often actually experiencing, civil strife, murder and genocide. Climate change also results in a lack of food and drought and leads to the migration of populations to unfamiliar and unwelcome territories, where they may be exposed to major epidemics such as human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), or endemic malaria and tuberculosis (TB). Emerging diseases include diabetes and cancer of the breast. While diabetes and associated obesity is an emerging epidemic of the middle class, all persons affected by lymphoedema tend to be immobile and gain weight. Furthermore, lymphoedema induces hypertrophy of adipose tissue. Delayed diagnosis of cancer and delays in the provision of its therapy are a more frequent cause of lymphoedema in the poor.

In addressing management there are many areas to be considered. There are several healthcare systems worldwide, and even in the UK many patients turn to other systems of health, such as alternative and complementary medicine, for help. There is also the influence of science, religion, and culture. Science encourages expensive high technology and gives little priority to research into low-cost systems of medicine that have a weak evidence base, even though there may be a long history of safe usage. Religion may condemn some systems of medicine as 'witchcraft'. Cultural factors are most evident in issues of sex and gender. Management must take into account the high prevalence of scrotal oedema, the importance of marriage and dowries that may be determined by good health and looks, and the differences in dress codes for women versus men.

There are also the areas of utilisation, safety and efficacy. If a therapy is widely used, it should be studied. Safety is of overriding importance. Biomedicine admits into hospital care more patients suffering from the side-effects of its prescribing than any other reason for admission. Some traditional medicine practices are dire, such as the use of dung on neonatal umbilical cords or the scarification of the skin to relieve

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internal disease, but, overall, side-effects from the prescription of a well-trained practitioner are rare and therefore advocacy for regulation should focus on training. Efficacy has many endpoints, including cure and also improved well-being.

Despite a large workforce that gives healthcare advice, there is much ignorance about oedema management. Education should be directed not just at the medical profession but nurses, pharmacists, podiatrists, and many others. Unfortunately, each profession tends to focus on the other's failures, and is unlikely to broadcast the other's successes. The complete education of those who give counsel requires an ability to negotiate values, taboos, beliefs and learnt ways of behaving. These negotiations may have to be directed at family members, school teachers and employers. Even the subtle estimates of different needs for children or older people requires some attention. For example, how do you estimate the amount of time that must be set aside to allow a child with a severe congenital cause of swelling to play and to learn to read and write?

Daily living and cost

Disability analysis has provided many questionnaires to estimate quality of life and the economics of daily living for people with disabilities. From the early estimates of the distance people can walk, to measurement of manual dexterity, was added the degree to which those who suffered from physical disabilities were actually welcome or felt welcome in company. Another factor that is difficult to measure and/or to eliminate, is the extra time taken to effectively self-manage disability.

Table I lists some activities that must be considered when estimating the cost of not being able to perform them. The question of how much unemployment has resulted from lymphoedema should also be added, and in Asia one might also consider the loss of dowry or failure to marry.

One important factor to reduce costs is the elimination of ineffective remedies, especially when they are expensive. For example, an incorrect diagnosis might lead to the inappropriate prescribing of diuretics for lymphoedema when there is no accompanying heart failure.

A great deal of money is spent on the 'look good, feel good factor', and many sufferers will tell you how they disguise their handicap by expensive clothing or how they manage the odour with perfumes or improved ventilation devices. The question of how much it costs to conceal an impairment also needs to be considered.

Table I

Examples of activities of daily living to consider when estimating the cost of not being able to perform them

- Looking after oneself: grooming, applying dressings, bandages and hosiery
- Mobility: bending, kneeling or stooping, climbing steps, undertaking exercise
- Washing clothes and household goods
- Daily work routine, including family care or travelling to work
- Going shopping
- Hobbies, i.e. gardening and holiday outings
- Sport
- Sexual activity with partner

If advances are to be made, the pharmaceutical and devices industries need to be involved. These industries need to survive while themselves having an expensive research and development burden. Those that do well can afford to be generous and there are many notable 'gifts' made by these industries, such as ivermectin by the Merck Foundation and albendazole from Glaxo SmithKline Beecham. On the other hand, some industries do advocate their wares with great intensity and pharmaceutical and devices industries who manage lymphoedema are often persuaded to prescribe goods that are expensive and not always cost-effective. It is in the developing world that one sees the most undesirable practices. The medical profession are bribed, out-of-date goods are sold by roadside sellers without data sheets, and many expensive new drugs are marketed without adequate evidence of safety and efficacy, as there is lack of supervision of regulation or corrupt practice.

Overriding all of these influences is the issue of poverty alleviation and the cost to the individual, the community and nation. World bank and other economic policies of the developed world have added cost-sharing to the burden of the poor.

Low-cost self-help

Management of lymphoedema is one of the disabilities most amenable to low-cost self-help. Management includes treatment of cause, promotion of lymphatic flow and reduction of the load on the lymphatic system. As a result of the Global Alliance of Lymphatic Filariasis (GAELF), the drugs for breaking transmission of the causative organism from the mosquito to the human are available free to whole populations, as a direct consequence of generous donations from the pharmaceutical industry. Cancer and its treatment by surgery and radiotherapy are, by and large, well-managed. There is, however, widespread ignorance about the role of the lymphatic system and the

management of lymphoedema. There have been huge improvements in the dissemination of knowledge in the UK in recent years, but it is slow to spread to rural sufferers and the poor in most parts of the world.

The private sector provides combined decongestive therapy (CDT) and manual lymphatic drainage (MLD), physiotherapy and aquatherapy. Telephone or written advice is usually not available to the poor, and illiteracy is common which will prevent the sufferer from being able to research the condition themselves. In addition, there are frequent needs requiring concordance with instructions, drugs, dressings, bandages, hosiery, special clothing and aids for moving around, including transport. The poor, given a list of precautions, will find they cannot conform and comply. They will often be unable to avoid carrying heavy objects, and are exposed to biting insects, heat, cold or sunburn and the frequent minor injuries of daily living.

It is necessary to promote lymph flow movement. While there are massage techniques that can do this, body movements are effective promoters of flow in a healthy lymphatic system. While studies in patients with lymphoedema are still required to prove some aspects of efficacy, no harm and probably some benefit at no cost comes from teaching subjects how to breathe and to move with correct posture, as in the Yoga practice of the Ayurvedic physician in India. To reduce the load on the lymphatic system, attention to venous load by elevating the limbs is likely to be helpful.

Items that are expensive are dressings, bandages and hosiery. Good evidence that one dressing, bandage system or stocking is much better than another is lacking, but they certainly range widely in price. In India, employment of a weaver to produce sheets of linen can provide hundreds of yards of exceptionally low-priced bandages. Washing and emollients can be inexpensive and can simply involve using jugs to pour water and local emollients such as coconut or mustard oil. Several trials have shown the value of hygiene in reducing recurrent inflammatory episodes. This, again, is a low-cost precaution. Herbal preparations used in India are a reminder that most plants learnt to deal with viruses, bacteria and fungi long before we did. They also share genes for the manufacture of antioxidants and other anti-inflammatory agents. One of the richest heads of state, now deceased, suffered from lymphoedema of the legs. He avoided inflammatory episodes by maintaining an intact skin by using an application of a honey lanolin mix — another low-cost solution.

The gold standard of proof comes from blinded randomised controlled trials. Unfortunately, for such complex therapies as lymphoedema management, these require a large number of patients and many exclusions. Such trials are exorbitantly expensive and in the fight to alleviate poverty, money can be better spent.

By focusing on the alleviation of poverty we can begin to reduce the suffering of the vast amount of the world's poor who have lymphoedema. By providing good advice, easy-to-follow instructions for self-management, and low-cost — or no-cost — treatment methods, we will go some way to improve the conditions for people with lymphoedema across the globe, as well as helping to break the cycle of poverty. JL