

HOPE CLUBS: A NEW STRATEGY FOR MORBIDITY CONTROL PROGRAMMES IN AREAS ENDEMIC FOR LYMPHATIC FILARIASIS

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An ambitious goal -- the global elimination of lymphatic filariasis as a public health problem -- was announced by the World Health Organization (WHO) two years ago. The principal strategy recommended by WHO for interrupting parasite transmission is annual mass treatment with either diethylcarbamazine (DEC) and albendazole or ivermectin and albendazole. The effectiveness of these drug combinations against intestinal helminths should enhance community acceptance of mass treatment for filariasis, but their lack of efficacy in reversing the chronic sequelae of filarial infection, including lymphedema, male urogenital disease (e.g., hydrocele), and hidden lymphatic damage, may also limit their acceptance.

Although astute clinical observations in the early 1900s and more recent data from animal models suggested a role for bacterial infections in the progression of lymphedema, during the past two decades these observations have been overshadowed by immunologic research, which hypothesized that disease progression resulted from immunologic responses to *Wuchereria bancrofti* or *Brugia malayi* infection. Observations that lymphedema and elephantiasis generally worsened with time, coupled with our lack of knowledge about how to reverse these immunologic processes, led to a sense of hopelessness among both physicians and patients regarding treatment of lymphedema in filariasis-endemic areas. Recently, however, data from several sites in India, Brasil, Ghana, and Haiti have shown that recurrent bacterial infections of the affected limbs are strongly associated with clinical worsening of lymphedema and elephantiasis. Prevention of these infections provides new hope for halting, or even reversing, progression of the disease.

For lymphedema treatment to be a major component of the global programme to eliminate lymphatic filariasis, it must be feasible at the community level, i.e., as a public health measure. The treatment must be simple, so patients can do it themselves, inexpensive, sustainable, and reproducible throughout the filariasis-endemic world. During the past 10 years, such a treatment regimen has been developed in Recife, Brasil. Based on hygiene, skin care, simple exercises, and elevation of the limb, this treatment regimen has been replicated in Haiti and is strikingly similar to those developed independently in Allepey, India and Tanzania. These principles have been summarized in a 16-page booklet, *New Hope for People with Lymphedema*^{*}. This booklet is available in English, free of charge, from the US Centers for Disease Control and Prevention; it is being translated into Portuguese, Arabic, Spanish, and French. The booklet is also available on the WHO filariasis web site www.filariasis.org/docs.

In filariasis-endemic areas, people with lymphedema tend to be more or less excluded from the normal life of the



community as a result of physical, social, and psychological barriers. This social isolation, when added to the belief that progression of the disease is inevitable, leads to dependency, passivity, and hopelessness. Our experience suggests that these tendencies can be reversed, and the sustainability of treatment ensured, by the creation of Hope Clubs, in which patients support each other and prepare themselves once again for full participation as human beings and members of society.

Hope Clubs are the result of an innovative approach that was launched seven years ago in Recife, Brasil, at the Aggeu Magalhães Research Center - FIOCRUZ. Currently the program is supported by the Federal University of Pernambuco and the Amaury Coutinho Non-Governmental Organization, created in December 1997. The aim of Hope Clubs is to equip lymphedema patients with the skills, motivation, and enthusiasm to sustain effective, low-cost, and convenient self-care for their lymphedema and to amplify these activities throughout filariasis-endemic communities. Through group participation and support, patients are encouraged to accept responsibility for the success or failure of their own treatment and to make the best use of their own resources (physical, emotional, social, and environmental).

Hope Clubs can provide significant benefits to patients and their communities, as has been observed in Recife. Patients with lymphedema come to realize that they are not alone; that they have access to simple, effective measures to prevent acute bacterial infections and relieve suffering; that they can regain their potential for productive work; that, as human beings, they have certain rights deserving of recognition and respect; that, as social creatures, they and their family members can work together to help each other and to solve problems through concerted action and cooperation; and, that through such action, they can produce sustainable, positive changes

within the community. For example, in Recife, where recent droughts have decreased access to clean water, patient-initiated community mobilization has resulted in establishment of community "foot-washing centers" where patients can gather and practice regular, daily hygiene.

Challenges to the spread of Hope Clubs in filariasis-endemic areas include passivity and hopelessness resulting from long-standing beliefs that no effective treatment exists; lack of access to clean water; lack of effective advocacy; and, to date, limited involvement of potential donors, including non-governmental development organizations, religious groups, and manufacturers of medical supplies and skin care products (e.g., anti-fungal creams). Increased involvement of such groups is needed to catalyze and solidify the growing network of organizations concerned with the "morbidity control pillar" of the global program to eliminate lymphatic filariasis as a public health problem.

WHO has described health promotion as the process of enabling people to increase control over, and improve their health. In Recife, Hope Clubs have acted as powerful agents of health promotion for people with lymphedema. Challenges remain to replicate Hope Clubs in other filariasis-endemic areas and to harness their positive energy for the goal of interrupting transmission of lymphatic filariasis. For example, Hope Club members can be strong advocates of mass distribution of antifilarial drugs. We believe that an international network of Hope Clubs -- by patients and for patients -- could contribute significantly to the growing consortium of public and private organizations committed to the elimination of lymphatic filariasis as a public health problem.

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^{*}Available in English, free of charge, from the US Centers for Disease Control and Prevention, Mailstop F - 22, Atlanta, GA 30341 - 3724, USA. It is being translated into Portuguese, Arabic, Spanish and French. The booklet is also available on the WHO filariasis website (www.filariasis.org/docs).