It is Possible: Availability of Lymphedema Case Management in each Health Facility in Togo. Program Description, Evaluation, and Lessons Learned

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Abstract. Lymphatic filariasis (LF) is a vector-borne parasitic disease that can clinically manifest as disabling lymphedema. Although the LF elimination program aims to reduce disability and to interrupt transmission, there has been a scarcity of disease morbidity management programs, particularly on a national scale. This report describes the implementation of the first nationwide LF lymphedema management program. The program, which was initiated in Togo in 2007, focuses on patient behavioral change. Its goal is two-fold: to achieve a sustainable program on a national-scale, and to serve as a model for other countries. The program has five major components: 1) train at least one health staff in lymphedema care in each health facility in Togo; 2) inform people with a swollen leg that care is available at their dispensary; 3) train patients on self-care; 4) provide a support system to motivate patients to continue self-care by training community health workers or family members and providing in home follow-up; and 5) integrate lymphedema management into the curriculum for medical staff. The program achieved the inclusion of lymphedema management in the routine healthcare package. The evaluation after three years estimated that 79% of persons with a swollen leg in Togo were enrolled in the program. The adherence rate to the proposed World Health Organization treatment of washing, exercise, and leg elevation was more than 70% after three years of the program, resulting in a stabilization of the lymphedema stage and a slight decrease in reported acute attacks among program participants. Health staff and patients consider the program successful in reaching and educating the patients. After the external funding ended, the morbidity management program is maintained through routine Ministry of Health activities.

INTRODUCTION

Lymphatic filariasis (LF) is a vector-borne helminthiasis caused by Wuchereria bancrofti, Brugia malayi, and B. timori. Nearly one-fifth of the world’s population is at risk in 72 countries.1 This disease is the second leading cause of disability worldwide, and there are an estimated 40 million persons with lymphedema and hydrocele, the main clinical manifestations of disease.1,2 Patients with lymphedema are also at increased susceptibility to adenolymphangitis attacks, also called acute attacks, that result in redness and swelling of the leg and can be accompanied by fever caused by poor lymphatic function and broken skin.3 Approximately 70% of the 120 million persons infected worldwide are asymptomatic, although most have subclinical, chronic damage to lymphatic and renal vessels.1 The World Health Organization recommends washing, leg elevation, and simple exercises as management of lymphedema and cooling and antipyretic drugs and if needed, antibiotics for adenolymphangitis attacks.

Studies have found among lymphedema patients in rural Africa, India, and the Dominican Republic that most patients either used no treatment or had unsuccessfully tried various traditional treatments, some of which were harmful.4–8 In addition, in spite of the significant need for social support, most patients in these studies believed that their emotional needs were unmet, inducing feelings of shame, isolation, and depression. These findings emphasized the need for a morbidity program. The economic burden of LF is also significant because of a combination of treatment costs incurred by patients and loss in work function. One study in India estimated the total disease cost at $842 million annually, or $2 per capita in the disease-endemic population.9

The World Health Assembly (WHO) passed resolution WHA 50.29 in 1997,10 which called for a collaborative effort to eliminate the disease as a public health problem by using the “Twin Pillars Approach”: 1) interruption of transmission of filarial infection in all disease-endemic countries through drastic reduction of microfilariae prevalence levels; and 2) prevention and alleviation of disability and suffering in persons already affected by LF.11 The Global Program to Eliminate LF, which began in 2000, has been successful in addressing the first pillar, averting LF infection in 6.6 million newborns and preventing development of chronic disease in 9.5 million patients with subclinical disease.12 However, there has been little progress in the second pillar. Evaluation studies have been conducted regarding the effectiveness of foot care programs and the feasibility of scaling-up these programs to a national, sustainable level.13–17 However, no nationwide programs exist in Africa and only a limited number of countries reported having a single morbidity program, with most existing on a small scale. This report describes the implementation of the first nation-wide LF lymphedema morbidity program in Africa.

METHODS

Program description. Togo is a country in western Africa with a population of 6.7 million, and 32% of the population live below the poverty line.18 The country is divided into 6 regions and 35 health districts. The district medical teams support 549 rural dispensaries nationwide. These dispensaries are the primary units of healthcare for the population and serve approximately 7,180 villages. The national LF program started in 2000 with baseline mapping followed by mass drug administration (MDA) in the seven LF-endemic districts (Figure 1).19 Based on existing data from different surveys,
it was estimated that 6,600–10,000 patients nationwide had lymphedema. In 2005, through funding by IMA World Health and the U.S. Agency for International Development, the Centers for Disease Control and Prevention (CDC) and Togo’s Ministry of Health developed an expanded novel approach to implement a national lymphedema morbidity program covering the country’s 35 health districts. The goal of the morbidity program was two-fold: to achieve national scale while remaining sustainable after startup costs were covered by external donors, and to serve as a model for other LF-endemic countries. The program rational centered on behavioral change, and increasing patient education and motivation to actively practice continued lymphedema care. With this tenet in mind, the program formula was simple, and was comprised of five main components Table 1.

Training. The first step in implementing the program was the training of at least one staff member in each health facility via the existing de-centralized health structure. During each phase of the program scale-up, the same approach was used. The national LF coordination team gave a two-day training session to the medical district directors and LF focal points of the targeted districts. A week later, staff from each district organized a two-day training for one nurse from each dispensary within their health district. Only conducted in LF-endemic districts, this training was followed by a one-day training for one community health worker (CHW) per village by the trained nurse. The CHWs were selected from among the village health workers assisting in MDA. Use of the training-of-trainers model ensured that in a period of 2–3 weeks all the relevant health staff was trained. The first phase of the program started in the LF-endemic areas and the next phases continued in non-LF-endemic areas.

The training consisted of theoretical and practical instruction in health education and disease management as recommended by WHO. A training manual, designed by the CDC and the Togo Ministry of Health, provided general information on LF and included detailed information with numerous illustrations on the management of lymphedema. In addition, this manual included all the tools necessary for program implementation, such as objectives and agenda for training each level of the healthcare system, checklist of supplies, and forms and copies of all the health education materials. The health education materials were adapted from WHO materials and were further adapted by a local artist to the context of Togo. This training manual was updated after each scale-up phase.

A total of 94 district health staff, 664 dispensary nurses, and 1,600 village volunteers were trained in 35 districts in approximately one year. Thirty-eight percent (n = 415) of the 1,083 lymphedema patients enrolled came from districts considered not to be endemic for LF.

During the initial training sessions, all necessary training materials were distributed and copies were stored at the district offices and the dispensaries. During trainings at district

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<th>Table 1: National lymphedema program: min components, Togo Morbidity Program</th>
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<tr>
<td>1) Train at least one health staff in lymphedema care at each of the 570 health facilities in the 35 districts</td>
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<tr>
<td>2) Inform people with a swollen leg that care is available at the local dispensary</td>
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<td>3) Diagnose and train patients how to care for their swollen leg</td>
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<td>4) Provide a support system to motivate the patients to take care of their leg</td>
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<td>5) Integrate lymphedema management into the curriculum for medical staff</td>
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![Figure 1. Scaling up of the Togo Morbidity Program: geographic area and persons trained.](image-url)
and dispensary levels, a patient was invited so that the staff could be provided with real life simulations. Basins, towels, and soap were supplied for this practical session.

**Sensitization.** Because the program was based on individual behavioral change, it was crucial that the patient took the first step to visit the dispensary and initiate the care and management process. Active case detection was not part of the chosen approach, although several nurses went to patient houses to notify them of the morbidity program. A variety of methods were used to disseminate the message that “anyone with a ‘big leg’ should go to the dispensary.” Administrative district officials contacted village chiefs and town criers, employing them to increase public awareness of the new lymphedema care program. In addition, the current health system was able to use their regularly scheduled community health education sessions to spread information regarding the new program. Locally created posters were hung in hospitals and dispensaries, schools, and town meeting places to expose the community to the idea that lymphedema was a disease and patients needed to go to the dispensary (Figure 2). During house-to-house visits for MDAs and vaccination campaigns, CHWs used photographs of lymphedema to sensitize the population. The CHWs were also provided with laminated posters for the community awareness campaign, which depicted lymphedema care and management techniques (Figure 2). Finally, radio messages were developed and transmitted through local radio channels in 12 indigenous languages. As soon as the program reached national scale, national radio messages, newspaper articles and a short TV documentary were used to further sensitize the population.

**Patient enrollment and start of treatment.** When a patient came to the dispensary with a swollen leg, the nurse diagnosed the patient and trained him or her (ideally along with a family member) in lymphedema care through a step-by-step demonstration on the patient’s swollen leg. The soap and towels used in the training were provided to the patient as a start-up hygiene pack. The patient also received a patient booklet, similar to the ones commonly used in the Togo healthcare system (Figure 3) to document the patient’s progress. The inside and back cover of the booklet depicted drawings demonstrating the treatment components and the treatment of an acute attack. Furthermore, upon induction into the program, a patient register was activated and kept at the local dispensary. In an attempt to maintain the sustain-ability of the lymphedema management program, patients were not given free treatment.

**Follow-up.** The protocol of patient follow-up differed depending on where the patient lived. In LF-endemic districts, patients were connected with the trained CHWs in their village. The CHWs used a laminated illustrated sheet depicting lymphedema management techniques to assist the patients. Each CHW was asked to visit the patient twice during the first week to ensure the patient had all the necessary materials to start the care. This patient was then monitored by regularly scheduled follow-up visits, which were initially weekly and then monthly. During each visit the CHW updated the patient booklet. The main purpose of the patient booklet was two-fold: 1) to offer key talking points to be addressed during each visit by the CHW or nurse for the purpose of increasing rapport and verbal communication; and 2) to produce an historical log of the lymphedema condition over time for the patient’s reference. The patient booklet provided additional space to enter clinical notes and care practices discussed during each visit. In addition, because it was a pilot program, the patient was asked to visit the dispensary every three months during the first year to follow clinical progress and was encouraged to continue dispensary visits throughout subsequent years in the program. Patient information and clinical manifestations during dispensary visits were also fully documented in the patient booklet.

In districts to which LF was not endemic, patient support was provided by a family member who was trained during the initial consultation, and intermittent follow-up was provided through recommended return visits to their dispensary. Although not initially planned by the program, the family members regularly recorded notes and patient details in the patient booklet because this feature was seen as a useful follow-up tool.

**Routine monitoring and evaluation of the program.** Every three months, the dispensaries were asked to send a copy of the lymphedema patient register to the district health team and the national LF coordinator. These data were entered into a Microsoft (Redmond, WA) Access database by the national coordinator. The district medical teams and the dispensary nurses were provided a budget for four supervisory visits per year. In addition, supervisory visits were conducted by the national morbidity coordinator and by the CDC on an annual basis.

![Figure 2](image_url)  
**Figure 2.** Health education materials: poster for the general public. **A,** Poster used by community health workers. **B,** Togo Morbidity Program.
Data to evaluate the program in more detail after three years were collected through 1) the patient register database; 2) one or more patient booklets from 341 patients living in LF-endemic districts; and 3) the final evaluation of the pilot program prepared through focused interviews with all stakeholders in the program in a representative sample of 11 health districts, 22 dispensaries, and more than 80 villages. During this evaluation, all persons in the selected villages with big legs were identified to determine the coverage of the program.

**Curriculum development.** Program sustainability heavily relied upon the requirement that all new health staff be trained in lymphedema management. The inclusion of the core principles of lymphedema management within the standard national medical curriculum for health officials, physicians, and nurses throughout Togo enabled greater penetrability of lymphedema care nationwide.

**Research.** An extensive list of indicators was followed to evaluate this pilot program, including adherence to treatment, incidence of acute attacks, and prevalence of clean skin. Other indicators assessed were impact of the program on quality of life and household buying power, as well as treatments used in the past and cost of treatments. Different collection methods were used including the yearly collection of the patient booklets in the endemic districts, evaluation visits, a three-year cohort survey of a convenience sample of 188 patients, and a final evaluation. Although the main results will be discussed in this report, the methods and detailed results are not the topic of this report.

**RESULTS**

The program achieved national scale in four phases over one year as planned (Figure 1). A total of 96 district health staff, 518 dispensary nurses from the public and private sector, and 1,600 CHWs were trained (Figure 4). In December 2010 (three years after the program began), the total number of
patients enrolled reached 1,083 and 38% of patients came from districts considered not endemic for LF. The final evaluation showed that among the randomly selected villages, 71 of the 90 persons with a swollen leg went to the dispensary for care, indicating 79% program coverage. The data from the patient booklets collected in the seven LF-endemic districts after year 1 showed that upon entrance into the program, 61% (208 of 341) of the patients were women with a median age of 48 years (range = 12–98 years). The median time since onset of symptoms was 17 years (range = < 1–68 years) with a patient median lymphedema stage of 3 Table 2. Median number of reported acute attacks by lymphedema stage at entrance into the program is shown in Table 3.

Data indicate that the acceptance and adherence to treatment practices was positive. An increase in the adherence to treatment practices was observed in the three-year cohort, which found that the practice of cleaning the limb increased from 10.3% (11 of 107) preprogram to 92.5% (99 of 107) after three years, exercising increased from 3.7% (4 of 107) preprogram to 78.5% (84 of 107) after three years, and elevation of the affected leg increased from 17.8% (19 of 107) preprogram to 76.6% (82 of 107) after three years (P < 0.0001). The average number of acute attacks was two per year at onset of the program. Nearly 74% (81 of 109) of patients in the cohort experienced either no change or a decrease in the number of reported acute attacks in year 1, 68.8% (n = 75) stayed the same, 5.5% (n = 6) decreased, and 6.4% (n = 7) increased, although results were not significant. The CHWs completed a median of nine visits to each patient annually (range = 0–10 visits), and 79% of the patients enrolled made yearly dispensary visits.

Evaluation visits disclosed the positive impact of the program on the daily life of the patients. Numerous testimonies were collected from patients reporting an improvement in their quality of life. After joining the program, patients reported their improved ability to walk and sleep, and some expressed their consolation in knowing a CHW would be coming to visit them. One patient shared, “I can see the booklet and be reminded of what I have done [by looking at the pictures] and realize that I am not alone. When someone follows up [in the booklet] it is encouraging.” Between year 1 and year 3 of the program, patients in the cohort reported increased activity and mobility, but among patients surveyed in 2007 and 2010, the proportion of patients who reported that their lymphedema symptoms prevented them from washing or getting out of bed increased from 0.0% to 7.6% (P < 0.01). However, the percentage of patients who reported these difficulties in 2010 remained low.

The cohort study in Togo found that the median overall cost of the treatment of a single acute attack, including payment to provider, travel, lodging, food, and cost of materials at baseline was $1.92 (range = $0–$336.54). The median overall cost for treatment of a single acute attack decreased over the three-year period, with median costs of $1.49 (range = $0–$67.79), $1.05 (range = $0–$34.62), and $1.25 (range = $0–$76.92) in 2008, 2009, and 2010, respectively. The median overall cost of lymphedema care, including payment to provider, travel, lodging, food, and cost of materials, at baseline was $5.00 per patient per year (range = $0–$1,173.08). The median overall cost for treatment of lymphedema care decreased over the three-year period, with median costs of $2.30 (range = $0–$2,365.38), $1.18 (range = $0–$769.23), and $1.01 (range = $0–$461.54) in 2008, 2009, and 2010, respectively.

The total cost of the program provided by donors, excluding the cost related to intense evaluation and operational research, was $155,721 (Figure 5). The main costs of the program were for training (44%) and supervision (17%), as well as increasing awareness and knowledge (30%) and the preparation and multiplication of health education materials (8%). The cost for each health facility trained was $234.52. Because the number of patients enrolled was less than expected, the cost of the program per patient was relatively high.

**DISCUSSION**

The Togo Ministry of Health’s lymphedema morbidity management program, which was implemented by the Togo Ministry of Health with technical support from CDC, is unique because it is the first lymphedema morbidity program to achieve a national scale in Africa. This program demonstrates that a nation-wide program is achievable and sustainable, even after external funding ended. As Togo stopped MDA for LF after the 2009 MDA, this program is also the
first free standing lymphedema program operating in the absence of an MDA program.\textsuperscript{19}

Within the span of one year, the program was operating at full capacity with a substantial magnitude of newly trained health staff ($n = 2,358$). The use of the training-of-trainers model enabled instruction in lymphedema care to be rapidly disseminated through multiple layers of the health system, including medical district director, nurses, and CHWs. This approach is in stark contrast with the accepted method that purports that lymphedema management can only be accomplished in specialized centers by highly trained experts, and that follow-up should occur in well-organized support groups.\textsuperscript{22}

Rather, the Togo morbidity program used the existing foundational network of CHWs whom had extensive experience caring for their population by dispensing of drugs during MDAs, in the follow-up of tuberculosis treatment, and in conducting rapid malaria testing. This feature is similar to that in many other countries who use CHWs for similar activities.\textsuperscript{23–25} The ability to use this extensive network of health staff enabled quicker implementation of services and ultimately more extensive patient enrollment. We found that 79\% of the patients identified during an evaluation were enrolled in the program and 79\% of the patients enrolled were making yearly dispensary visits.

The final evaluation showed that the number of patients was much lower than expected. The reasons for the overestimation of the burden in the years before the onset of the program are not clear. We found a high mortality in our cohort study, but possible other hypotheses include problems with differential diagnoses or, as indicated in a study in Tanzania, the positive effect of Mectizan given during MDAs.\textsuperscript{26} The way that MDAs are launched when the threshold for public health intervention is reached, we do not believe that a precise number of patients has to be known before action is taken. All medical staff is trained in training hypertension and prevention campaigns are organized, and we know the exact number of patients with hypertension in a country. In addition, in contrast with most programs that are using focal resources (specialized clinics, subsidized focus groups), it was decide to roll out a program that trains at least one health staff in each health facility nationwide with the cost of the program independent of the number of patients.

This lymphedema management program was purposely designed to heighten patient capability in the consistent performance of treatment and self-care practices. Training the CHW or family member to keep regular interactive sessions with the patient was intended to facilitate continual motivation and supportive oversight of treatment practices and annual appointments. A subsample of patient booklets demonstrated the program’s success in achieving high self-reported patient adherence to the maintenance of the daily treatments of washing, exercising, and elevating the affected leg after year 1 of the program.

The increase in patient activity, as seen in the general positive feedback from the patients, is most likely not only caused by effective treatment but also by empowering of patients to no longer see themselves as passive victims to their disease now that they know what to do. A multiplicity of patients voiced their happiness of increased mobility and self-sufficiency. We hypothesize that patient improvement was not only physically displayed by an increase of daily exercises and washings but more importantly, engaging in these activities appreciably improved patient psychological health and well-being. We believe that the success of the program relied also on the sensitization campaign’s capability to inform the whole population that lymphedema is a disease caused by a parasite and not a curse or punishment. We also hypothesize that the decreased cost of managing acute attacks and decreased cost of lymphedema care are attributable to the lymphedema patients’ new found ability to manage their own disease and avoid unnecessary treatments that may be expensive or harmful.\textsuperscript{5,26}

The large number of patients found living in districts to which LF is not endemic illustrates the need for national lymphedema morbidity programs to cover all national health districts, including those not endemic for LF. The explanation of high enrollment in non-endemic districts could be explained by migrant populations within and exterior to country boundaries; and by districts that were previously endemic for LF but where the transmission was interrupted before the 2000 mapping.\textsuperscript{27}

In conclusion, the lymphedema program implemented in Togo has met its goals. First and foremost, it has succeeded in delivering care to a population in need. It has met a crucial secondary goal by demonstrating that a sustainable national

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\caption{Percentage of program costs, Togo Morbidity Program.}
\end{figure}
lymphedema morbidity campaign can be achieved. The program was economically and organizationally feasible; it had high patient coverage and adherence to treatment; the structural framework facilitated ease of staff training, message dissemination, and patient care; and major program components were successfully integrated into existing health infrastructure.

Finally, this program was able to demonstrate that even after a country has addressed the first pillar of disease elimination, a morbidity program is still requisite, given the continued burden of morbidity that persists long after transmission has been interrupted. When external funding ended for this project, the lymphedema morbidity program became part of the national health package provided by the health structures in Togo and continues to this day. A similar approach has been taken by the Ministry of Health in Mali to implement a large-scale lymphedema management program. The documents developed are also used by other partners, such as Handicap International. For this reason, the manual, which contains all materials needed to implement a national program, is regularly updated and is shared with the international community.

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