A survey of treatment practices and burden of lymphoedema in Togo

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Summary Lymphatic filariasis, a mosquito-borne parasitic disease, can lead to lymphoedema and elephantiasis. This study describes the results of a baseline survey of a lymphoedema morbidity management programme in Togo. A convenience sample of 188 people with lymphoedema was asked about symptoms, treatment preferences and quality of life. Those with higher stage lymphoedema were more likely to have experienced an acute attack (odds ratio = 1.9; \( P = 0.002 \)). Although only 28.2\% of those surveyed reported currently using any lymphoedema treatment, 80.3\% had used treatments in the past, primarily traditional products (68.1\%) and scarification (38.8\%). Medication was the preferred treatment for acute attacks, both currently (73.1\%) and in the past (61.7\%). Patients reported difficulties performing activities such as walking to the field (44\%) and carrying a heavy load (63\%) as a result of their lymphoedema. Patients felt avoided by their family (17\%) and their community (36\%). Using the Duke Anxiety—Depression scale, over 70\% of patients were found to be at high risk of depression and this risk increased with lymphoedema stage \((P = 0.04)\). The survey results demonstrate the need for a morbidity management programme that will increase the use of morbidity management techniques and decrease the physical and emotional burden of this disease.

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1. Introduction

Lymphatic filariasis, a mosquito-borne parasitic disease, is a major contributor to disability in the developing world (Ottesen et al., 1997). Although infection is generally asymptomatic, the presence of the adult worms is believed to cause irreversible damage to the lymphatic vessels that can lead to lymphatic insufficiency, hydrocele,
lymphoedema and, ultimately, elephantiasis. People with lymphatic filariasis may also suffer from recurrent secondary bacterial infections, commonly known as acute attacks, characterised by inflammation, swelling and pain. Acute attacks are a major contributing factor to the progression of morbidity from asymptomatic infection to lymphoedema and elephantiasis (Dreyer et al., 2002).

In 1997, the World Health Assembly called for the elimination of lymphatic filariasis as a public health problem (WHA 50.29) and two approaches are being used to reach this goal (Ottesen et al., 1997). The first approach is the prevention of new infections through interruption of transmission with mass drug administrations (MDA). The second approach is morbidity management to decrease the suffering resulting from the chronic manifestations of the disease. Morbidity management involves surgical interventions such as hydrocelectomy as well as simple and inexpensive patient activities, including hygiene, exercise and elevation of the affected body part to limit the progression of lymphoedema (Dreyer et al., 2002). These activities have been demonstrated to be effective in improving physical health and quality of life for lymphoedema patients (McPherson, 2003; Suma et al., 2002; WHO, 2004).

Togo is a small country on the west coast of Africa, with 7 of 35 health districts being endemic for lymphatic filariasis caused by *Wuchereria bancrofti* infection (Gyapong et al., 2002). The climate is tropical, hot and humid in the south part of the country and semi-arid in the north. There are approximately 37 ethnolinguistic groups in the population of over five million people. The estimated at-risk population in Togo is 1.06 million (WHO, 2005). At the time of the survey, the country had undertaken two to four annual rounds of MDA in the endemic districts. Togo does not currently have an active morbidity management programme, and little is known about local treatment-seeking behaviours and burden of disease. The primary goal of this survey was to provide baseline data for the evaluation of a proposed nationwide morbidity management programme. In addition, this survey provides insight into treatment preferences of Togolese patients and supplements existing data regarding the physical and psychological burden of lymphoedema of the leg.

2. Methods

The survey was conducted at the beginning of the dry season in six of the seven lymphatic filariasis-endemic districts. The dominant ethnolinguistic groups of the country were represented in the sample, such as Ewe (Haho district), Akposso (Amou district), Kabye (Kozah and Binah districts), Tem (Doufelgou district) and Moba (Tone district). A convenience sample was taken among persons with lymphoedema of the leg, defined for this survey as having at least one swollen leg. Eligible persons were identified by asking market vendors, village chiefs, school children and others whether they knew of anyone with this symptom. Verbal consent was obtained prior to beginning the interview and the survey was approved by both the Togo Ministry of Health and the CDC Institutional Review Board as a programme evaluation activity.

Three pairs of interviewers conducted the survey, with each pair consisting of one person trained specifically to use a personal digital assistant (PDA) and to administer the questionnaire and one medically trained person who spoke the local language and was recruited locally. The questionnaire comprised a structured set of questions and pre-defined responses and was translated verbally from French into local languages, many of which are not written languages. Interviewers were given the option to type in an answer if the patient’s response did not fit into the available choices. The interviewers entered the respondents’ answers using the PDAs and photographed the patients’ legs using disposable cameras.

The survey included four broad categories of questions: general patient information; lymphoedema; acute attacks; and quality of life. General patient information collected included name, age, gender, marital status, address, occupation, ethnicity, education level and religion. The interviewers collected information on the clinical history of lymphoedema and noted the presence of lymphoedema characteristics (reversible or irreversible swelling, shallow or deep skin folds, knobs, lesions), whether the affected limb had an odour or was unclean (visible dirt and/or herbs), the type of lymphoedema treatment sought, the cost of treatment (not described in this paper) and the treatment providers. Patients were asked about treatments they utilised currently and those they had tried in the past. The types of treatment used by the patient were categorised broadly; for example, the application of leaves, mud or herbs was categorised as ‘traditional products’. If the patient mentioned that they changed their diet in any way to decrease symptoms, the treatment was categorised as ‘dietary changes’; and any medication mentioned, from aspirin to antibiotics, was categorised under ‘medication’. Other general categories of treatments include scarification (a series of small cuts made on the swollen limb), herbal infusion and washing or elevation of the affected limb. Patients were not asked whether they had participated in a MDA. The lymphoedema symptom data were used during analysis to categorise lymphoedema severity into seven stages according to the scheme developed by Dreyer et al. (2002) (Table 1). The photographs of the legs were reviewed by CDC epidemiologists familiar with lymphoedema staging to verify the stage classification scheme. Stage was determined for both of the patient’s legs, and the stage of the more severely affected leg was used in analysis. For example, if a patient had stage 4 lymphoedema in his left leg and stage 2 lymphoedema in his right leg, in analysis his lymphoedema would be classified as stage 4.

Acute attacks were defined as an illness where the affected limb becomes swollen and hot in the presence of fever. Patients were asked whether they had ever experienced an acute attack. If so, they were asked how many attacks they had experienced since the beginning of the year and the average acute attack duration. Patients described the types and costs of treatment they used for their acute attacks and from whom they sought treatment, both currently and in the past.

Quality of life was assessed by asking about lymphoedema-associated impediments to activities in life and feelings of support, shame and isolation. In addition, the Duke Anxiety—Depression (DUKE-AD) scale was used to quantify risk for depression in this population. This scale has been used primarily in Western populations to identify patients who are at high risk for depression.
and/or anxiety disorders (Parkerson and Broadhead, 1997; Parkerson et al., 1996). The scale includes seven questions with a standardised method of score calculation and a cut-off score (>30) indicating high risk for depression. The scale was considered both as a continuous (total score) and dichotomous (based on the cut-off) variable.

All analyses were performed using SAS (SAS Institute Inc., Cary, NC, USA). Comparison of survey responses was performed using chi-square analysis for categorical variables and Student’s t-tests for continuous variables. Current and past treatment choices were compared using McNemar’s test for paired data. Logistic regression was used to quantify the likelihood of having experienced an acute attack with increasing stage. Stage was considered both as a continuous variable and was categorised into three groups (1 and 2, 3 or >2). Owing to sample size limitations, age was considered as a binary variable with two categories: <50 years and >50 years (mean age of participants 50.2 years). In all comparisons, a P-value of ≤0.05 was considered to be statistically significant.

3. Results

3.1. Demographic characteristics

A total of 188 patients were interviewed, of whom 102 (54.3%) were women. Most of the lymphoedema patients were married (115; 61.2%), practiced traditional African religions (animism) (106; 56.4%) and had never attended school (116; 61.7%). The average age of the surveyed patients was 50.2 years (range 6–90 years) and the patients were primarily farmers (93; 49.5%), vendors (25; 13.3%) and craftsmen (13; 6.9%). Almost one-quarter of the patients reported having no occupation (45; 23.9%).

3.2. Lymphoedema or swelling

The interviewers recorded the history and physical description of the patients’ lymphoedema. Patients reported that the swelling began an average of 18.0 years previously (range 1–60 years, median 15 years) and became debilitating (interfering with work or daily life) an average of 11.8 years previously (range 1–55 years, median 10 years). Lymphoedema stage assigned by CDC epidemiologists from the photographs taken by the interviewers was not statistically significantly different from the stage derived by the symptom classification scheme (weighted κ = 0.79; P = 0.44); therefore, the stages calculated from the original data were used. Of the patients surveyed, 27.7% had stage 1 or 2 lymphoedema, almost one-half (45.7%) had stage 3 lymphoedema and 26.6% had stage 4 or higher lymphoedema (Table 1). No statistically significant differences were found in lymphoedema stage by gender or age. Bilateral swelling was observed in 73 (38.8%) of the patients, 37 (50.7%) of whom had symmetrical swelling. Interviewers recorded that 61% of the patients had legs that were unclean (visible dirt and/or herbs). Ninety-eight (52.1%) of the patients had entry lesions (breaks in the skin through which bacteria can enter) on their legs or feet, 55 (56.1%) of whom had entry lesions between their toes. Men were more likely to have entry lesions (odds ratio (OR) = 1.9; P = 0.04) and unclean legs (OR = 2.4; P = 0.005) than women.

Patients were asked about which activities they performed to treat their lymphoedema both in the past and currently (Table 2). In the past, a wide variety of treatments had been tried by the 188 people surveyed, including traditional products (68.1%), scarification (a series of small cuts made on the swollen limb) (38.8%), herbal infusions (31.4%) and dietary changes (14.9%). Few patients reported practicing washing (1.6%) and elevation of the limb (8.0%), and no patients reported practicing range of motion exercises in the past. Although most patients (80.3%) reported having tried at least one method of treatment in the past, far fewer patients (28.2%) reported currently doing anything to treat their lymphoedema and this difference was statistically significant (P ≤ 0.001). The most frequently reported currently practiced treatments for lymphoedema included traditional products (19.1%), herbal infusions (8.5%) and medication (8.0%).

The use of particular treatments was not statistically significantly associated with religion or education. Men were more likely than women to use traditional products (OR = 2.5; P = 0.02), dietary changes (OR = 6.6; P = 0.01) and elevation of the limb (OR = 4.4; P = 0.05). The only treatment that was statistically significantly associated with age was past use of scarification. Younger people (<50 years of age) were more than twice as likely as older people to have tried scarification (OR = 2.2; P = 0.008).

Patients had primarily sought care for their lymphoedema from traditional healers (71%), health post nurses (30%) and district health staff (26%). People who practiced traditional African religions were twice as likely to seek out traditional healers (71%), health post nurses (30%) and district health staff (26%) than people who identified themselves as Muslim or Christian (OR = 1.9; P = 0.05). Any education (≥ 1 year of school) was associated with the use

<table>
<thead>
<tr>
<th>Stage</th>
<th>Lymphoedema characteristics</th>
<th>No. of patients (%)</th>
<th>Patients with entry lesions (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Swelling reversible overnight</td>
<td>32 (17.0)</td>
<td>12 (37.5)</td>
</tr>
<tr>
<td>2</td>
<td>Swelling not reversible overnight</td>
<td>20 (10.6)</td>
<td>8 (40.0)</td>
</tr>
<tr>
<td>3</td>
<td>Shallow skin folds</td>
<td>86 (45.7)</td>
<td>38 (44.2)</td>
</tr>
<tr>
<td>4</td>
<td>Knobs</td>
<td>7 (3.7)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>5</td>
<td>Deep skin folds</td>
<td>10 (5.3)</td>
<td>6 (60.0)</td>
</tr>
<tr>
<td>6</td>
<td>Mossy lesions</td>
<td>33 (17.6)</td>
<td>28 (84.8)</td>
</tr>
<tr>
<td>7</td>
<td>Unable to care for self or perform daily activities</td>
<td>(0.0)</td>
<td>(0.0)</td>
</tr>
</tbody>
</table>

Table 1: Lymphoedema staging (Dreyer et al., 2002), number of patients in each lymphoedema stage and number with entry lesions, Togo.
of district health facilities (OR = 3.7; \( P < 0.001 \)), as was male gender (OR = 2.1; \( P = 0.03 \)). No other statistically significant associations were noted between the patient characteristics (age, sex, education, religion) and their choice of treatment providers.

3.3. Acute attacks

Most patients (167; 88.8\%) reported having experienced an acute attack. Each one-stage increase in lymphoedema was associated with a two-fold increased risk of having experienced an acute attack (OR = 1.9; \( P = 0.002 \)). No association was observed between having experienced an acute attack and gender, education, limb cleanliness or age (\( P > 0.05 \)). Among the 167 patients who reported ever experiencing an acute attack, 139 (83\%) reported experiencing one during the past year, with an average of 2.3 attacks in the past year (range 0–12 attacks, median 2 attacks) and an average acute attack duration of 7.3 days (range 0–90 days, median 5 days). Acute attacks interfered with most patients’ daily activities (144/167; 86\%), and an average of 11.0 days of work (range 0–60 days, median 7 days) were lost per acute attack. Among those who reported having had at least one acute attack, no association was noted between lymphoedema stage and frequency (\( P = 0.18 \)) or duration (\( P = 0.36 \)) of acute attacks. The most commonly used treatments for acute attacks in the past included medication (primarily aspirin and antibiotics) (61.7\%), traditional products (41.3\%) and herbal infusions (19.8\%) (Table 2). When past and current treatment preferences were compared, far fewer people currently used traditional products (\( P < 0.001 \)), herbal infusions (\( P = 0.002 \)) and scarification (\( P = 0.05 \)) than in the past. Medication was more frequently reported as a current treatment for acute attacks than in the past (\( P = 0.05 \)). Education and gender were not statistically significantly associated with any of the treatment options. Those who practiced traditional African religions were more than twice as likely to have treated an acute attack with a traditional product compared with those who identified themselves as Muslim or Christian (OR = 2.3; \( P = 0.04 \)). People <50 years of age were more than five times more likely to report the use of scarification as a treatment for their acute attacks than were older individuals (OR = 5.2; \( P = 0.002 \)).

Patients sought treatment for their acute attacks from a variety of sources, including traditional healers (53\%), family members (37\%) and dispensary nurses (28\%). Those patients who practiced traditional African religions were almost twice as likely to seek treatment from traditional healers as those who identified themselves as Muslim or Christian (OR = 1.89; \( P = 0.04 \)). No other statistically significant associations were noted between the patient characteristics (age, sex, education, religion) and their choice of treatment providers.

Different methods were used to treat the acute and chronic manifestations of lymphatic filariasis. Medication was far more likely to be used to treat acute attacks than to treat lymphoedema, both currently and in the past (\( P < 0.001 \)). In the past, scarification was more commonly used to treat lymphoedema than acute attacks (\( P < 0.001 \)). Currently, few people practice scarification to treat either condition. Patients also sought out different people to provide treatment for the two conditions. Patients were far more likely to seek out traditional healers or medical agents for lymphoedema treatment than they were for acute attacks (\( P < 0.001 \)). Patients reported relying on family members for treatment of acute attacks more often than was reported for lymphoedema (\( P < 0.001 \)).

3.4. Quality of life

Patients were asked a number of questions about whether they had trouble performing different activities during the past week. Few patients reported having trouble feeding (2/188; 1\%), dressing (5/188; 3\%) or washing (11/187; 6\%) themselves, but many patients reported having trouble in the past week with activities that require physical exertion such as fetching water (23/104; 22\%), walking to the market (50/161; 31\%) or to the field (73/166; 44\%), or carrying

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### Table 2  Treatments used by Togolese patients for swollen legs and acute attacks, now and in the past, Togo (several answers were possible)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Swollen legs (( n = 188 ))</th>
<th>Current (%)</th>
<th>Past (%)</th>
<th>Treatment</th>
<th>Acute attacks (( n = 167 ))</th>
<th>Current (%)</th>
<th>Past (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing</td>
<td>135 (71.8)</td>
<td>37 (19.7)</td>
<td></td>
<td>Medication</td>
<td>122 (73.1)</td>
<td>103 (61.7)</td>
<td></td>
</tr>
<tr>
<td>Traditional product</td>
<td>36 (19.1)</td>
<td>128 (68.1)</td>
<td></td>
<td>Traditional product</td>
<td>37 (22.2)</td>
<td>69 (41.3)</td>
<td></td>
</tr>
<tr>
<td>Herbal infusion</td>
<td>16 (8.5)</td>
<td>59 (31.4)</td>
<td></td>
<td>Herbal infusion</td>
<td>16 (9.6)</td>
<td>33 (19.8)</td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>15 (8.0)</td>
<td>21 (11.2)</td>
<td></td>
<td>Ointment</td>
<td>11 (6.6)</td>
<td>13 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Change in diet</td>
<td>12 (6.4)</td>
<td>28 (14.9)</td>
<td></td>
<td>Scarification</td>
<td>8 (4.8)</td>
<td>17 (10.2)</td>
<td></td>
</tr>
<tr>
<td>Bandages</td>
<td>10 (5.3)</td>
<td>9 (4.8)</td>
<td></td>
<td>Ice</td>
<td>4 (2.4)</td>
<td>11 (6.6)</td>
<td></td>
</tr>
<tr>
<td>Elevation</td>
<td>9 (4.8)</td>
<td>15 (8.0)</td>
<td></td>
<td>Warm compress</td>
<td>4 (2.4)</td>
<td>3 (1.8)</td>
<td></td>
</tr>
<tr>
<td>Prayer</td>
<td>5 (2.7)</td>
<td>8 (4.3)</td>
<td></td>
<td>Prayer</td>
<td>2 (1.2)</td>
<td>4 (2.4)</td>
<td></td>
</tr>
<tr>
<td>Warm compress</td>
<td>6 (3.2)</td>
<td>22 (11.7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scarification</td>
<td>5 (2.7)</td>
<td>73 (38.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washing</td>
<td>3 (1.6)</td>
<td>3 (1.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>1 (0.5)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compression</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Comparison between past and present use of treatments using McNemar’s test: \( P \)-value \( \leq 0.05 \).
Table 3 Comparison of help needed and offered as perceived by the lymphoedema patient, Togo

<table>
<thead>
<tr>
<th>Potential source of help</th>
<th>No. (%) of patients needing help from potential source</th>
<th>No. (%) of patients reporting that help was offered from potential source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family, immediate</td>
<td>140 (74.5)</td>
<td>125 (66.5)</td>
</tr>
<tr>
<td>Family, extended</td>
<td>124 (65.9)</td>
<td>75 (39.9)</td>
</tr>
<tr>
<td>Friends</td>
<td>107 (56.9)</td>
<td>56 (29.8)</td>
</tr>
<tr>
<td>Community</td>
<td>79.0 (42.0)</td>
<td>32 (17.0)</td>
</tr>
</tbody>
</table>

heavy loads (69/109; 63%). Almost one-half of the patients reported that their lymphoedema had prevented them from engaging in activities with their friends (51/106; 48%).

Questions were also asked about the patients’ relationships and interactions with others. When asked whether they needed any help with daily activities during the past week from different groups of people, 42% of patients reported needing help from their community, 57% from their friends, 66% from their extended family and 74% from their immediate family (Table 3). Offers of help with daily activities during the past week, however, were insufficient and the unmet needs increased with distance from the immediate family. During the past week, 17% of patients felt avoided or rejected by their family (immediate and extended) as a result of their lymphoedema, 29% of patients felt avoided or rejected by their friends and neighbours and 36% felt avoided or rejected by their community. When considering only patients with stage 4 lymphoedema and above, the proportion of those feeling rejected increased dramatically; 30% felt avoided by their family, 46% by their friends and neighbours and 60% by their community. Over 50% of patients felt that their health was not as good as the health of those around them, and 15% of patients did not know how their health compared with others.

Finally, patients were asked about their attitudes and beliefs concerning their illness and life in general. Isolation and shame were problems in these patients; 55% of surveyed patients felt isolated, that there was nobody to talk with about their illness, and 62% of the patients were ashamed of their lymphoedema. Men and women were equally likely to feel isolated (P > 0.1), but women felt more shame as a result of their lymphoedema than men (OR = 1.99; P = 0.02).

Feelings of isolation and shame were more common among those with higher stages of lymphoedema (P = 0.05). Regarding the future of their illness, most patients did not know whether their lymphoedema would get worse (80%) or if it would be cured (57%).

Risk of depression was assessed using the DUKE-AD scale. Over 70% of patients met the criterion (DUKE-AD score >30) to be considered at high risk for depression. Risk for depression was not statistically different in men and women (P > 0.1). Patients with higher stages of lymphoedema were more likely to be at high risk for depression than those with lower stages (P = 0.04). Patients who had experienced more than one attack in the past year were twice as likely to be at high risk for depression than those who had experienced one or no attack (P = 0.04). Patients at high risk for depression reported almost twice the number of days per year with an acute attack (7.5 days) than those who were below the DUKE-AD cut-off (4.0 days) and this was statistically significant (P = 0.04). Number of days lost from work due to lymphoedema was also statistically significantly different between patients classified as at high risk for depression (11.8 days) and those who were not (4.5 days) (P < 0.01). High risk for depression was strongly associated with feelings of isolation (OR = 7.0; P < 0.001) and shame (OR 3.5; P < 0.001).

4. Discussion

These survey results provide insight into the treatment practices and preferences of Togolese people living with lymphoedema as well as the burden of the disease on these patients. This information will primarily be used for evaluation purposes in determining the effectiveness of a planned morbidity management programme in Togo. In addition, the results can be used by the morbidity management programme to identify stakeholders in programme development and to identify current, potentially harmful practices that should be addressed, and therefore to craft a more acceptable and effective programme.

The burden of lymphoedema appears to be quite high, particularly when one considers patients’ activities, relationships and attitudes. Many patients had difficulties performing activities that required mobility and were therefore probably limited in their ability to provide for their families. This adverse effect on activity level has been demonstrated in India, where 66% of all patients reported impaired ability to perform daily activities (Ramaiah et al., 1997). Lymphatic filariasis results not only in the physical manifestations and limitations of lymphoedema and acute attacks but also in feelings of shame, rejection and isolation associated with disability. Also, as a result of their disability, patients overwhelmingly said they needed help from others during the past week and, unfortunately, all of their needs are not being met, particularly by their friends and by the community at large.

Few previous studies have investigated quality of life, specifically depression, with regard to lymphoedema. A qualitative study in Haiti illustrated the social and economic burdens of lymphoedema in women (Coreil et al., 1998). In Guyana, researchers used the Dermatology Life Quality Index (DLQI) to evaluate quality of life in lymphoedema patients before and after receiving morbidity management training. They found that the baseline quality of life was poor in lymphoedema patients but they did not observe a strong association between lymphoedema stage and DLQI score, presumably because coping mechanisms may be employed the longer a person has a disease (McPherson, 2003). Another study used an extended form of EuroQol to determine the physical and psychosocial burden of acute attacks and lymphoedema and found that higher stages of lymphoedema were associated with more severe psychosocial problems (Krishna et al., 2005). Similarly, this survey in Togo found a high risk of depression to be more common among patients with higher stages of lymphoedema than among people with earlier stages. High risk of depression was also found to be associated with the number of acute attacks experienced in the past year and...
the number of days missed from work due to acute attacks. This indicates that although coping mechanisms may be utilised over time, they may not compensate for the pain and embarrassment associated with acute attacks and lymphoedema in general. These results further underscore the need for a morbidity management programme, since naturally acquired coping mechanisms, even if employed, are not sufficient to maintain a reasonable quality of life for these higher stage patients.

Our survey results also provide insight into the treatment preferences and burden of lymphatic filariasis in the survey participants. In the past, patients used a variety of methods to treat their lymphoedema but far fewer continue to seek treatment. One possible explanation for the decrease in treatment-seeking behaviour over time may be that the treatments are generally found to be unsuccessful or, in the case of scarification, exacerbate the condition of the leg. Another possible explanation for this decrease is the patient’s increasingly limited resources as the disease progresses and it becomes more difficult to earn a living and support a family. Regarding WHO recommended morbidity management treatments, very few patients had ever tried hygiene, exercise and elevation of the limb. It seems that in the absence of morbidity management programmes, these techniques may not arise naturally; therefore, programmes should be developed in which patients are taught the recommended activities to slow lymphoedema progression (Nanda and Ramaiah, 2003). Traditional healers were the most commonly cited source of lymphoedema treatment; therefore, morbidity management programmes will benefit from their participation and support. The survey responses indicate that a Togolese morbidity management programme should include the WHO recommended morbidity management activities, information about acute attacks and treatment recommendations, and explicit guidance against the use of scarification. Patients should be trained in morbidity management along with at least one family member, and it is hoped that this will increase the family support available to the patient and therefore improve their quality of life.

Treatment seeking for acute attacks was more common in this population (82% reported at least one preferred treatment) than was found in previous studies in Ghana and India where only 55% and 49%, respectively, of patients with acute attacks sought any type of treatment (Gyapong et al., 1996a; Ramaiah et al., 1998). The primary difference between this survey and the studies in Ghana and India is that this survey was cross-sectional, whereas the Ghana and India studies were longitudinal studies. Although we asked the patients about their current treatment preferences for acute attacks, they were not necessarily experiencing an acute attack at the time of the survey so there is the potential for recall bias. In addition, since acute attacks frequently only last approximately 1 week, even patients who recognise that certain treatments are helpful may not utilise them if the cost of treatment is considered too high.

Scarification is a treatment that is of particular interest owing to its potential to exacerbate symptoms of lymphatic filariasis and lead to rapid progression to elephantiasis (Dunyo et al., 1997). Over one-third of those surveyed (38.8%) said that they had tried scarification in the past to treat their lymphoedema, although only 2.7% of the patients said that they currently practiced scarification. It is unclear why the majority of people do not currently practice scarification, but the decrease in frequency is encouraging. A morbidity management programme is likely to decrease further the current use of scarification through education and alternative treatment options.

Higher lymphoedema stage was associated with increased risk of having ever experienced an acute attack, but no association was found between stage and frequency or duration of acute attacks. The lack of association between stage and frequency/duration of acute attacks concurs with the results of two previous studies of acute attacks in Africa (Gasarasi et al., 2000; Gyapong et al., 1996b) but differs from the results of other studies that did find an association between stage and frequency of attacks (Pani et al., 1995; Shenoy et al., 1999). It has been hypothesised that the contrasting findings may be the result of different study designs and recall periods, but this survey uses the same recall period as the Pani study (12 months), with contrasting results. There may indeed be basic differences between populations in the pathology of lymphoedema, and further investigation is needed.

This survey has several limitations. Owing to low lymphatic filariasis morbidity prevalence, a convenience sample was taken, which may not be representative of the full spectrum of morbidity associated with lymphatic filariasis. Also, since Togo has many ethnolinguistic minorities, one potential problem with the survey is that it had to be verbally translated from French to the local language by the interviewers. To maintain consistency between interviewers and in the different languages, the interviewers underwent extensive training regarding the precise meaning of each question in order to translate it correctly in the field. Another limitation of this survey is the cross-sectional nature of the data. These data provide a snapshot of practices and attitudes related to lymphoedema in this population but care must be taken when considering the recall bias that occurs when you ask someone about things that may have happened many years ago (previously used treatments, for example). However, recall bias probably does not greatly impact on our conclusions since our primary item of interest is activities that are currently performed.

Togo is currently addressing the first approach to lymphatic filariasis elimination through annual MDAs. The second approach of lymphatic filariasis elimination, i.e. morbidity management training in order to stem the progression of lymphoedema in affected patients, is planned for the future. As the survey results demonstrate, the current treatment practices of Togolese patients do not include the WHO recommended morbidity management techniques, and the physical and psychosocial burden of lymphatic filariasis in this population is quite high. These baseline survey data underscore the need for a morbidity management programme and provide information for tailoring it to the population, including current healthcare-seeking behaviours of those with lymphoedema and their beliefs about the disease. In addition, the effectiveness of this programme will be evaluated by comparing follow-up surveys with this baseline survey. It is hoped that a morbidity management programme in Togo will provide inexpensive, effective and easily adapted alternatives to currently available treatment options and will therefore decrease both the physical and psychosocial burden of lymphatic filariasis.
Conflicts of interest statement
The authors have no conflicts of interest concerning the work reported in this paper.

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