

Can We Overcome the Key Programme Issues to Improve Filarial Lymphoedema Follow-Up Schemes?

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ABSTRACT

Introduction: Lymphoedema management is one of the two main strategies executed by the national programme to Eliminate Lymphatic Filariasis (PELF). We addressed three key programmatic issues at national level (1) locating patients, (2) educating patients, family members on practice of lymphoedema self-care (3) well sustained daily self-care.

Methods: All 117 lymphoedema patients of Matara recorded by Yahathugoda, *et al.* (2005) were assembled for instruction on Community Home Based Care (CHBC). 107 of them introduced to the CHBC programme again at their homes. The lymphoedema management protocol (Dreyer, *et al.* 2002) had five components: (1) hygiene, (2) prevention and cure of entry lesions (EL), (3) exercise, (4) elevation of affected limbs (5) protection of limbs. 27 patients were followed-up under two schemes, 14 in Daily follow-up (DFU) scheme and 13 in Monthly follow-up (MFU) scheme. To measure the impacts of the two different schemes, a KAP score of management protocol, number of EL and acute attacks, limb volume, its appearance, changes in the quality of life and gained benefits were assessed after one year.

Results and Discussion: (1) **Locating patients:** Only 51.4% participated in the community gatherings. Non-attendees were shy to be in public. However, visiting patients at home to introduce the programme was successful. (2) **Education of patients and family members:** Both groups showed similar overall KAP scores on lymphoedema care while the scores on most important techniques such as frequency of cleaning, rinsing and drying of limb/s, management of toe webs etc., were significantly higher in DFU group. (3) **Encouragement and support for daily self care:** Number positive for EL and mean acute attacks per year reduced from 50.0% to 14.3% ($P=0.063$) and 5.0 episodes to 0.2 ($P<0.001$) respectively in DFU group whereas MFU showed 53.8% to 23.1% ($P=0.13$) and 3.3 to 1.3 ($P<0.021$) reduction. The mean oedema volume in DFU group reduced significantly from 2,426.2 mL to 2,262.7 mL ($P<0.02$), whereas it slightly increased from 2,672.3 mL to 2,704.1 mL in MFU group. Photographs with obvious improvements in limb size and skin appearance will be valuable for propaganda and education. The modified DLQI mean score reduced significantly from 4.6 to 2.0, ($P<0.01$) in DFU group, whereas MFU group was very close to the significant level ($P=0.07$). Benefit score at one year revealed that the patients in DFU group received significantly higher benefits compared to MFU group.

Conclusion: Daily instruction has significantly motivated the patient and his/her family bringing a new hope.

INTRODUCTION

Acute inflammatory episodes (AIEs), lymphoedema and hydrocoele are the three major manifestations of Lymphatic Filariasis (LF) (Addiss & Brady, 2007). The prevalence of filarial lymphoedema in three suburbs of Matara town, Sri Lanka was estimated to be 3% and that of hydrocoele 6.2% in early 2000 (Weerasooriya *et al.*, 2001). Perera *et al.* (2007) scaled up the previous estimates to the whole population at risk (10 million) and gave an expected 300,000 cases of lymphoedema and around 300,000 males with hydrocoele in the country. As for AIEs, 46.6% to 58.4% of lymphoedema patients experienced the episode at least once in Sri Lanka (Chandrasena *et al.*, 2004; Yahathugoda *et al.*, 2005; Wijesinghe *et al.*, 2007a). However, the annual incidence of AIEs per patient was lower in Sri Lanka up to 1.1 attack/year (Chandrasena *et al.*, 2004; Wijesinghe *et al.*, 2007a) compared to that of Tamil Nadu, India (6.4, Krishnamoorthy *et al.*, 1999), or Kerala, India (7.6, Pani *et al.*, 1989). Almost all lymphoedema cases suffer physically, psychologically and socially to a significant extent (Chandrasena *et al.*, 2004; Yahathugoda *et al.*, 2005; Wijesinghe *et al.*, 2007b).

Having such serious public health problems with LF, national Programme to Eliminate Lymphatic Filariasis (PELF) has initiated its activities in 2002. Community Home-Based Care (CHBC) approach was selected to alleviate and prevent both the suffering and the disability caused by the disease (Ottesen, 2000, Dreyer *et al.*, 2002).

The main objective of CHBC is to ensure that individuals who are not fully capable of the long-term self-care can maintain the best possible quality of life with the greatest possible degree of independence, autonomy, participation and personal fulfillment by activities carried out at home by themselves or informal carers (family, friends and neighbours), formal carers, traditional carers and/or volunteers (WHO, 2004).

WHO has provided support to the pilot projects in Madagascar, Sri Lanka and Zanzibar, where the CHBC protocol described by Dreyer *et al.* (2002) (lymphoedema management protocol, hereafter) was employed. In Sri Lanka, patients were monitored at a clinic by a doctor, and in the other two countries a community- and a family-based approaches were adopted. Irrespective of the approaches, significant reduction of AIEs was seen in these projects (WHO, 2004). Similar successful results were observed by Wijesinghe *et al.*, 2007a in Sri Lanka following the lymphoedema management protocol. However, most of these studies focused on AIEs reduction and few studies have documented the effectiveness or impact of the management protocol on such parameters as leg volume, entry lesions, odour, stage of lymphoedema and quality of life. Further, none of the programmes have evaluated the frequency and intensity of education/training required for patients to become competent in self-care of lymphoedema (Addiss & Brady, 2007). In this study, a special attention was paid to analyse improvements in all these parameters along with AIEs. For that, in this interventional study, the efficacy of a daily follow-up scheme and a monthly follow-up scheme was compared after one year of treatment.

METHODS

Study area & Study subjects

The subjects enrolled for the study lived in three inter-connected suburbs—Polhena, Walgama and Madihe—immediately west to the town of Matara.

Yahathugoda *et al.* (2005) registered 117 lymphoedema patients in the same area and a detailed study was conducted using 101 of them. In the present study, 107 of the 117 were introduced to the CHBC programme at their homes (2 cases refused to join and 8 were absent). The ethical clearance for the morbidity management study protocol was obtained from the Ethical Review Committee of the Faculty of Medicine, University of Ruhuna, Sri Lanka.

Community Home-Based Care (CHBC) approach for management of lymphoedema

Under CHBC programme, the lymphoedema management protocol described by Dreyer, *et al.* (2002) was applied. The protocol has five components: (1) hygiene, (2) prevention and cure of entry lesions (EL), (3) exercise, (4) elevation of an affected limb and (5) protection of limbs.

'Community meetings' to educate patients on the CHBC programme: This activity was initiated in April 2006 covering the three suburbs, and all 117 lymphoedema patients recorded by Yahathugoda *et al.* (2005) were invited. Five meetings were conducted. A multimedia presentation on lymphoedema care was done, then management protocol was demonstrated step by step, using 2 to 4 patients who were attending the meeting. The steps demonstrated briefly, nail care including identification of ingrown nail and fungal infections to be treated promptly, EL identification and care/treatment, careful washing and drying of the limbs, elevation of the limbs while sleeping using a homemade pillow placed under the foot-end of the mattress, maintaining the affected leg elevated during work and leisure time, usage of proper slippers to protect feet and exercise of the limbs. Also at the meetings, probable carers of patients were identified.

'Meeting patients and their caregivers at their homes' to educate them on the CHBC programme: The writer (TCY), another medical officer and two field assistants (FAs) visited all registered patients house by house to introduce lymphoedema care. At home, patients and caregivers could be trained in more detail than at the community meeting. A washing place was identified, elevation the foot-end of the mattress was practiced, and even alteration of furniture arrangements with household consent was made to facilitate patient's limb elevation during leisure time.

Monitoring the lymphoedema care programme using two different follow-up schemes

A purposive sampling was used to select a group of subjects who would stick to the instructions. They were those suffering lymphoedema Grade II or more with or without EL, had a history of AIEs and with fixed house address. There were 27 such patients in all (Table 1). Those who had history of neoplasm, myocardial infarction, chronic obstructive pulmonary disease and severely debilitated status were not included. They were divided into 2 groups: 14 who had their homes close by were selected for a daily follow-up scheme and the balance 13 was followed up monthly by a doctor (monthly follow-up scheme).

Daily follow-up (DFU) scheme: Two FAs were trained for this task on the 1st week. FAs were trained on communication skills, problem identification, lymphoedema management protocol, identification of EL, identification of AIE/cellulitis, basic medication for EL and a referral system in the case of AIE/cellulitis. Each FA was given a 'field bag' containing a pen-torch, thermometer, bottle of potassium permanganate, bottle of 70% surgical spirit, gauze and cotton wool, latex gloves, scissors, two tubes each of anti-bacterial and anti-fungal topical applications. From the 2nd week onwards, each FA covered 7 households, spending about one hour with each patient. They identified problems, conducted lymphoedema management with the help of the patient and family supporter and recorded findings. After 4-5 weeks the patient and his/her caregiver started daily lymphoedema care by themselves, while FA encouraged and advised them technically. The writer (TCY) or another medical officer visited all 14 households once per week.

Monthly follow-up (MFU) scheme: Other 13 households were visited once a month to motivate, advise and train them for proper lymphoedema care. In the case of AIE/cellulitis, those patients were treated.

Assessment of levels of Knowledge, Attitude and Practices (KAP) on lymphoedema management protocol

To measure impacts of two different schemes of follow-ups (DFU and MFU) on KAP, an indirect questionnaire method was used before CHBC and after 1 year. KAP scores were based on 22 questions (Table 2). An answer to each question was given a score of 0, 1, 2, 3, 4 or 5, a larger number indicating more satisfaction.

Baseline and one-year assessments to measure the success of lymphoedema care programmes

Assessment of the presence of EL: Irrespective of the number and size, if found, they were identified as EL positive patients and recorded.

Assessment of frequency of AIEs: For each patient in DFU and MFU groups, the total number of AIEs occurred in 1 year prior to the introduction of lymphoedema care (AIEs/year) was computed using monthly records of these patients kept by the writer (Yahathugoda *et al.*, 2005), and taken as a baseline frequency. After 1 year, AIEs/year was computed individually based on daily records for DFU group and monthly records for MFU group.

Measurement of volume of limbs: A water displacement technique was adopted to measure the volume of lower limbs up to 30cm. Both lower limbs were measured with care to obtain accurate volume. Each patient was measured for limb volume again by the same examiner at the same place and time after one year of lymphoedema care.

Photographic evidences to assess the appearance of limbs and skin hygiene: A baseline photograph of both lower limbs was taken in the seating position. Angle and distance of the camera, other camera specifications and the positioning of the limbs were noted. Another photograph was taken 1 year later from each patient in accordance with the previous specifications of photography.

Assessment of quality of life: Dermatology Life Quality Index (DLQI) by Finlay and Khan, (1994) was used to assess the quality of life (QoL) of lymphoedema patients. Questions (1) and (2) assess the symptoms and feelings, (3) and (4) daily activities, (5) and (6) leisure, (7) work/school, (8) and (9) personal relationship, and (10) treatment. An answer to each question was given a score of 0, 1, 2, or 3, a larger number indicating less satisfaction. The DLQI is calculated by summing up the scores of all questions, making the maximum of 30 and the minimum of 0. The higher the total score is, the more QoL is impaired.

Slight modifications to DLQI method were made to use in local setups. They were as follows: (1) the questions were modified to focus on both skin conditions and an oedematous lesion of the limb instead of the skin alone, (2) it assessed conditions in the latest 1 month and (3) interviews were conducted to obtain DLQI scores. These modifications were validated by Chandrasena *et al.* (2007). The same DLQI was used to assess QoL after one year following lymphoedema care.

Assessment of benefits: Another study was conducted to assess benefits gained by lymphoedema management, using a questionnaire. The questions are classified under 3 categories, short-term, intermediate-term and long-term benefits (Table 3). There were 12 questions, and an answer to each question was given a score (benefits score) of 0, 1, 2, 3, 4 or 5, a larger number indicating more satisfaction.

Statistical analysis

Before intervention, the comparability between DFU and MFU groups was tested. Then, before and after lymphoedema management, the occurrence of EL was compared with all 27 patients (McNemar's χ^2 test), and within DFU or MFU group (McNemar's χ^2 test), and after intervention, between DFU and MFU groups (Fisher's exact test). Similarly, the means of AIE frequency, oedema volume and DLQI score were compared before and after oedema care with 27 patients (paired *t*-test) and within DFU or MFU group (paired *t*-test), and after intervention between DFU and MFU groups (Student's *t*-test). For KAP and benefit scores, DFU and MFU groups were compared using Mann-Whitney U test.

RESULTS

Before starting lymphoedema care programme, both DFU and MFU groups had comparable parameters on sex, age, and clinical signs.

Measurements of success

Levels of Knowledge, Attitude and Practices (KAP) on CHBC protocol: All the average scores recorded for specific questions were higher in DFU group compared to those of MFU-Group (Table 2). Under 'washing limbs', KAP on most important parts of the management protocol such as special care of toe webs and skin folds and careful drying after washing were significantly higher DFU group compared to that of MFG(all $P < 0.05$).

Significantly higher scores for wearing slippers inside the house to protect limbs were recorded in DFU group compared that of MFU group ($P < 0.05$). Scores for careful EL management was

higher in DFU group than MFU group but not significant ($P=0.10-0.11$). Under 'elevation of limbs', the average scores for leisure time and day-to-day work at home were significantly higher in DFU-Group ($P<0.01$). Both groups scored the lowest averages for the 'exercise of limbs' with no difference between the groups.

Improvement of EL: The presence/absence of EL before and after one year of follow-up in DFU and MFU groups is listed in Table 1. Analyzed in each group, the reduction from 50.0% (7/14) to 14.3% (2/14) in DFU group was close to a significant level ($P=0.063$), but the reduction from 53.8% (7/13) to 23.1% (3/13) in MFU group was not significant ($P=0.13$).

Frequency of AIEs: Analyzed by group, the mean of 5.0 episodes (range: 0 – 12) before the introduction of lymphoedema management reduced to 0.2 after one year in DFU group ($P<0.001$) (Table 1). The reduction in MFU group from 3.3 to 1.3 was also significant (paired *t*-test, $P<0.021$).

Measurement of volume of the lower limb: The change in the volume is shown individually in Table 1. The mean volume in DFU group reduced significantly from 2,426.2 mL to 2,262.7 mL after one year ($P<0.02$), whereas it slightly increased from 2,672.3 mL to 2,704.1 mL in MFU group, though this was not significant ($P=0.25$).

Photographic evidence of improvement in the appearance of limb and skin hygiene: Photographs were taken from each patient before and after lymphoedema management. Twenty of 27 paired photographs did not show any visible change. In all, 5 in DFU group (case Nos. 2, 3, 8, 11, and 12) and 1 in MFU group (case No. 23) showed improvement in oedema size or skin conditions whereas 1 of MFU group (case No. 20) showed increased lymphoedema (Table 1). Figures 1.1 – 1.3 show three obvious improvements in DFU group. All oedema changes noticed in the photographs were confined to the dorsum of foot and the ankle area except case No. 11, whose oedema reduction was mainly seen in the calf area (Figure 1.1). Apart from the oedema volume, mossy lesions in the case No. 12 disappeared almost completely (Figure 1.3), and in the case No. 8, shallow skin folds disappeared after one year of lymphoedema care (Figure 1.2).

Improvement of quality of life (QoL): DLQI score reduction in DFU group from 4.6 to 2.0 was significant ($P<0.01$), and in MFU-Group, it showed a tendency of reduction (from 3.5 to 1.7, $P=0.07$).

Benefit score: Average scores under 3 categories of benefit are shown for DFU and MFU groups in Table 3. Under short & intermediate-term benefits, higher scores were recorded in both DFU and MFU groups (>3), however, scores recorded for 'motivated with new hope' and 'acceptance by the family' were significantly higher in DFU group ($P<0.05$). When long-term benefits were considered all scores were higher in DFU (ranged between 2.86-5.00) than scores of MFU group (1.23-4.00) and difference of most benefit scores were significant ($P<0.05$).

DISCUSSION

The present study addressed several key programmatic issues to improve lymphoedema management protocol at national level. The challenges were (1) finding patients and bring them to treatment, (2) education of patients and family members on the principles and practice of lymphoedema self-care and (3) encouragement and support to sustained daily self-care (Addiss & Brady, 2007).

(1) Finding patients and bring them to treatment: Under current practice in the national PELF, patients are monitored through monthly doctor's appointments at a clinic. However, a field-based study by Yahathugoda, *et al.* (2005) showed 64 of 101 (63.4%) patients did not seek care from the government-clinic in three suburbs of Matara town. The main reason was that they were too shy or too embarrassed by their lymphoedema to attend the clinic. Further, some cases were compelled to hide their condition from spouse and family (Perera, *et al.*, 2007). The long distance to the only clinic in Matara town (~5 Km) from the study area could be another reason. A similar behaviour was shown by patients, when 'community meetings' were held to bring them to treatment. Only 51.4% participated in the meetings.

Visiting patients house-by-house to introduce lymphoedema care programme was a success. Almost all the cases and their caregivers learned lymphoedema management protocol in a much friendlier environment compared with the community meetings. Patients and their families were highly motivated with our visit to their homes. Some said, "*This is the first time a medical personnel visited our house and talked to us*", and another said, "*This is the first time somebody touched my limb*". House visits provided opportunities to identify available resources and utilize them to scale-up the management protocol.

(2) Education of patients and family members on the principles and practice of lymphoedema self-care: Hardly any research has been done to assess the frequency and intensity of education required for patients to become competent in lymphoedema self-care (Addiss & Brady, 2007). Several studies carried out to introduce the lymphoedema care had identified the importance of periodic reinforcement of the management protocol in the long-term sustainability of KAP on such protocol (Wijesinghe, *et al.*, 2007a; Suma, *et al.*, 2002; Shenoy, *et al.*, 1999). In the present study, two monitoring schemes were tested. DFU group had daily reinforcement of the lymphoedema management while MFU group had monthly boosts. Both groups showed reasonable KAP scores on lymphoedema care. However, the scores on most important techniques such as frequency of cleaning, rinsing and drying of limb/s, management of toe webs—cleaning and drying, care to non-affected limb/s, wearing slippers inside the house and keeping limb/s elevated during day time were significantly higher in DFU group. All patients were advised to wash their limbs at least once daily. DFU group was visited by a trained field assistant on a daily basis, which led them to washing of limbs before their day-to-day activities, whereas MFU group was visited only monthly. Therefore, in MFU group daily washing was missed due to several factors. One patient's spouse said, "*When he started washing first he did it very well. Recently he had fever attacks so he could not wash the limb regularly. We encourage him to wash the limb but he walks around a lot. That is why he gets fever.*" An unmarried brother and sister said, "*We have to earn the living. My sister and I wash the limbs when we have time*". Another male patient said "*I earned my living as a salesman in the sea-shore, so my limbs*

get automatically washed with sea water frequently. Whenever I have time I tried to wash the limbs as instructed but the swelling has not reduced". MFU group tended to neglect the fact that special attention should have been given to toe-web cleaning and drying. A patient said, "I wash the limb when I wash the face and take a bath. But I forget to wash the toe clefts properly with pieces of cloth put in between regularly".

Though the average score for wearing slippers inside house was significantly higher in DFU group, it was below par in both groups. Patients in both groups said that they were not used to wear slippers specially inside the house and it was very difficult to make it a habit. A majority tended to neglect their lymphoedema because it did not cause any acute severe pain. In fact a patient said, *"I did not use slippers indoors earlier. But I had a swelling and severe pain in the other knee (diagnosed as osteoarthritis) and I received treatment from Teaching Hospital Galle. There I was advised to use slippers regularly. Now I use slippers both outdoors and indoors because I don't want to get that joint pain again".* Patients in DFU group were subjected to the handling of field assistants, therefore they kept their limb elevated even during day-to-day work in the kitchen. This may be a reason why the average KAP score for limb elevation during day time was significantly higher in DFU group. However, persuading patients to do limb exercises in both DFU and MFU groups did not meet with much success. This was not due to the lack of knowledge but laziness and negligence by patients. The previously mentioned woman who had acute attack of osteoarthritis of a knee-joint, practiced regular exercises. She said, *"I was taught exercises at the hospital for the limb with knee swelling which was very similar to exercises trained by filariasis team. I did them because I did not want the knee pain to recur. I did the same exercises to my other limb with swelling. Then the swelling reduced very much."*

The significant results observed in DFU group would suggest that a volunteer could be trained to deliver KAP on lymphoedema management protocol, to identify EL, AIEs and other related problems successfully. McPherson and colleagues have used health workers in Guyana, with limited training, to diagnose lymphoedema grading and identify EL with a success (McPherson, *et al.*, 2006). The present study pioneered using lay persons (Post GCE – Advanced Level students) as volunteers to do the similar task in CHBC with a great success. However, diagnosis of filarial lymphoedema and highly complicated grading of lymphoedema should be done first by a trained doctor.

(3) Encouragement and support to sustained daily self care: Sustained daily lymphoedema care mainly depends on the satisfaction of the patient. This was the reason why we selected a group of people by purposive sampling to show that the lymphoedema management protocol would be effective. Depending on the satisfaction of the patients, and for general satisfaction, it is essential to provide people with visible success in reducing EL, AIEs and leg volume by use of lymphoedema self care. However, including the majority of the 107 cases of lymphoedema would have revealed a more realistic view of what actually happen in the community when exposed to CHBC.

Effectiveness of the lymphoedema care on EL: Dreyer and colleagues observed that the prevalence and severity of EL could be dramatically reduced with basic lymphoedema management (Dreyer, *et al.*, 2002). A clinic-based study in Sri Lanka observed 76.1% (124/163) of lymphoedema patients with ELs, which significantly reduced to 52.1% (85/163) after one year of lymphoedema

care. In the same study they observed that lymphoedema management protocol was mainly effective in reducing inter-digital infections, ingrown nails, cracks in soles and skin-fold lesions. Chronic ulcers and eczemas might need different approaches from simple lymphoedema care (Wijesinghe, *et al.*, 2007a). In the present study 51.9% (14/27) had EL either in inter-digital spaces or skin-folds or both. At one year it reduced significantly to 18.5% (5/27). However, the EL reduction in each of DFU and MFU groups, and after-one-year EL prevalence between two groups were not different statistically. This may be due to small sample size.

Effectiveness of lymphoedema care on AIEs: Dreyer, *et al.*, (1999) defined two distinct clinical entities under AIE: acute filarial lymphangitis (AFL), caused by death of adult worm(s), and acute dermatolymphangioadenitis (ADLA), associated with secondary bacterial infection. However, studies carried out in Sri Lanka have considered AIEs as episodes of limb pain (ELP) (Yahathugoda, *et al.*, 2005) or ADLA (Chandrasena, *et al.*, 2004) or adenolymphangitis (ADL) (Wijesinghe, *et al.*, 2007a) without making a clear separation of AFL and ADLA. In the present study, due to difficulty to differentiate them in the field, both were studied under AIEs. Both in DFU and MFU groups, the mean numbers of AIE/year reduced significantly. A clinic-based study carried out in Sri Lanka showed a similar reduction of the mean AIE with patients who had grade 2 or higher lymphoedema (Wijesinghe, *et al.*, 2007a). Other endemic countries, such as Kerala, India (Suma, *et al.*, 2002; Shenoy, *et al.*, 1995), Orissa, India (Kerketta, *et al.*, 2005), Haiti (Addiss, *et al.*, 1999; 2003) and Guyana (McPherson, 2003) also observed a marked reduction in the incidence of AIEs as an impact of basic package of lymphoedema management.

Effectiveness of lymphoedema care on leg volume: A few studies have documented changes in leg volume or circumference in response to basic lymphoedema management (Addiss & Brady, 2007). The present study used water displacement technique to measure volume of limbs. The mean volume of lymphoedema was significantly reduced among 27 patients and DFU group at one year. A study carried out in Orissa, India observed similar improvement in lymphoedema volume following basic foot care (Kerketta, *et al.*, 2005). To achieve a significant lymphoedema volume reduction, very careful and regular lymphoedema care is needed. The patients in MFU group might not pay such close attention to limb care, which would explain a slight increment in volume, a clear contrast to the people in DFU group. At one year, the mean limb volumes of the two groups were not different significantly. A small sample size may be a part of reason. But there will be other reasons. Paired test (within DFU and with 27 patients) will give significant result more easily than non-paired test. Reduction of volume seems to be not big (average about < 10%) of the pre-treatment value, therefore this may not influence Mann-Whitney U test much.

Effectiveness of lymphoedema care on appearance of limbs and limb-skin: Minor changes in the volume or skin appearance will not be noticed in a photograph. In the present study, at least 10% reduction in edema volume was required to be recognized. Thus with photographs, only 7 of 27 showed obvious alterations, improvements in 6 and aggravation in 1 case. A reduction in lymphoedema grade was seen in the case No. 8 (from III to II) and No. 12 (from VI to V). Despite a remarkable volume reduction in the case No. 11, there was no such change in grade. This is not unexpected because the staging system was not developed based on edema size (Addiss & Brady, 2007).

Photographs with obvious improvements in limb size and skin appearance will be valuable for propaganda and education. In fact, we have used the photograph of case No. 11 as a success story to encourage other lymphoedema patients. We observe that this case has been rumored in nearby village and some patients outside the study area visited us seeking lymphoedema care. Some of the carers/supporters tend to quote this patient and encourage the own patient to achieve the same target.

Effectiveness of lymphoedema care on QoL and benefits gained: A study carried out in Guyana documented a significant reduction of DLQI score following introduction of a hygiene and skin care protocol for lymphoedema patients. The present study used the same DLQI to measure QoL with slight modifications (Chandrasena, *et al.*, 2007). The modified DLQI mean score reduced significantly from 4.1 to 1.9 among 27 patients after one year of lymphoedema care. A similar significant reduction was seen in DFU group (from 4.6 to 2.0, $P < 0.01$), and the mean score reduction in MFU group was very close to the significant level ($P = 0.07$). This will be in relation to the fact that significant improvement of AIEs was seen in both groups. AIEs are the main cause which results in a high DLQI.

Benefit score at one year revealed that the patients in DFU group received significantly higher amount of benefits compared to MFU group: Daily talk and touch have significantly motivated the patient and his/her family bringing a new hope. Other short-term benefits such as accepting lymphoedema care as a life-long requirement and a sense of well-being were also experienced by the majority in DFU group. However, both groups gained reduction/elimination of bad odour of affected limb/s as a short-term benefit of lymphoedema care. The daughter of a patient said, *"There were lots of ulcers on the limb, we could not help him because of bad smell. Now, the ulcers of the limb have reduced and no more bad smell. This is really a very useful thing. Now, we can help him to wash the limbs"*. A majority of patients said, *"No more bad smell like earlier"*. These anecdotes have accentuated the fact that reduction in bad odour as an outcome of lymphoedema care has an important effect on QoL (Addiss & Brady, 2007). Since both groups showed a similar reduction pattern of EL and AIEs, intermediate-term benefits gained were similar between the groups. The mother of a young patient said, *"We owe you a great deal for all the help you have given. Now there is no fever, ulcers have healed and the swelling has also reduced very much"*. The spouse of a patient said, *"The fever episodes have reduced very much. Earlier every month she used to consult a doctor to seek treatment for attacks of fever with redness of the leg"*. Many patients as well as their caregivers said, *"One of the worries we have was resolved, that is frequent episodes of fever"*. The present study emphasized that to gain long-term benefits such as elimination/reduction of dependency, socialization and reduction in oedema size could be achieved only by daily talk and touch. On the other hand, monthly care could provide some of the short-term and intermediate-term benefits. A patient in DFU group said, *"Now I can go anywhere; to the temple or to a neighbour's place without fear. Swelling is very much less than it used to be."* Then the neighbour of the same patient commented, *"She does not get fever now. The swelling of the leg has reduced very much."* Another patient from the same group said, *"It is a big relief to me mentally. I feel a reduction in limb swelling up to a certain extent. But I cannot attend to exercise since I am busy. But skin crease on the upper surface of the foot that has been there for a time has disappeared. Skin is smoother than before. No fever attack at all. It is a big thing."* A few such anecdotes were seen in MFU group.

Conclusion: A significant alleviation of AIEs and EL was observed after one year in both monitoring schemes. In the long term, DFU-scheme was better since it provided significantly higher KAP scores on lymphoedema management protocol, benefit score, significant reduction of limb volume, and significant improvement in QoL compared to MFU-scheme.

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