

Short paper

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## Impact on the quality of life of lymphoedema patients following introduction of a hygiene and skin care regimen in a Guyanese community endemic for lymphatic filariasis: A preliminary clinical intervention study

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### Abstract

**Background:** Hygiene and skin care are effective and important interventions in the management of lymphoedema secondary to lymphatic filariasis. We analyzed the impact on the quality of life that education and introduction of a designated nurse had on lymphoedema patients in a community that was endemic for lymphatic filariasis.

**Methods:** Patients' life quality was assessed using a Dermatology Life Quality Index (DLQI) questionnaire. At the same time they received education on appropriate hygiene, skin care techniques and simple exercises that encourage lymph drainage. A designated nurse was provided with educational materials and treatments. The DLQI life quality measure was repeated one year later.

**Results:** The DLQI improved for all patients and reported acute attacks were reduced. A paired t-test showed the improvement in DLQI to be highly significant ( $P = < 0.0001$ ).

**Conclusions:** A nurse-led service combined with patient education in communities endemic for lymphatic filariasis is an effective intervention in improving the quality of life of patients with lymphoedema.

### Background

Lymphatic Filariasis (LF) leads to permanent lymphatic dysfunction in virtually all infected individuals and clinical disease in a subset of these [1]. A major sequelae of infection is lymphoedema of the limbs – whereby lymphatic dysfunction can lead to swelling of the limbs which becomes permanent and, with repeated painful episodes of bacterial lymphangitis, known as 'acute attacks', causes considerable acute morbidity and progression of lymphoedema to elephantiasis [2].

In common with other skin diseases, lymphoedema has a negative impact on patient quality of life. However most studies on the impact on quality of life have been in the developed world on post-mastectomy patients [3,4]. Lymphoedema secondary to lymphatic filariasis has not been clearly assessed or compared with other skin conditions.

The Dermatology Life Quality Index (DLQI) is a questionnaire that has been shown to be an accurate way of assessing the effect skin disease has on quality of life [5]. The DLQI contains ten questions which assess how skin dis-

ease has been affecting the individual's quality of life over the past week and covers symptoms, feelings, daily activities, leisure, work, personal relationships and treatment. Each question can score 0–3 points with the total range being 0–30 [See additional file 1].

As a measure of life quality the DLQI has been validated in the United Kingdom and applied to many skin conditions world wide including in developing countries [6,7]. Furthermore, the DLQI has recently been validated as a tool to monitor changes in quality of life [8]. There has not yet been any published work on its use with lymphoedema patients. This study introduces the use of the DLQI for patients with limb lymphoedema. It was used in this setting, rather than a general health inventory to measure quality of life, as this study was looking in particular at the impact of the introduction of a hygiene and skin care regimen to patients.

Work has shown that the model, established in Brazil by Gerusa Dreyer, of hygiene and skin care is the most effective treatment for lymphoedema secondary to LF [9–11]. Unpublished work in Haiti has already shown a positive impact on disease and certain measures of life quality by implementing this model [Dahl B, personal communication]. Further work is needed to see if these interventions can work in other LF endemic regions.

Guyana is a low-income country on the Caribbean coast of South America with a population of 750,000, concentrated in the coastal region. The Guyanese Ministry of Health, with support from Pan American Health Organization (PAHO), recently established a national programme to address LF and its public health implications. Mapping exercises completed last year show that the prevalence of lymphatic filariasis in Guyanese school children [as determined by the presence of Circulating Filarial Antigen (CFA)] is as high as 45% in some areas. In Wismar, the study area, CFA prevalence was found to be 33%. There was no information on morbidity, or any formal programme to provide disease sufferers with support until 2001 when PAHO and the World Health Organization (WHO) began working with the Ministry of Health on this issue.

Initial work on morbidity was carried out in Guyana between April and June 2001, at the same time as this study was being initiated. This involved use of clinic data and interviews with health workers and patients including a testing of the applicability of the use DLQI in a sample of patients in the vector control clinic in Georgetown. These investigations revealed a significant burden of disease and a poor level of knowledge of the mechanisms of the disease and effective treatments. There was haphazard and inconsistent care, with poor facilities for lymphoedema

patients, and a feeling of impotence among health care workers and patients. The initial interviews for this study were carried out at the inception of Guyana's national LF programme and before the introduction of any morbidity programmes either nationally or locally.

This short paper reports on the effect on the quality of life of lymphoedema patients following introduction of a hygiene and skin care regimen in one community endemic for lymphatic filariasis in Guyana.

## Methods

Wismar is a municipality within the bauxite-mining town of Linden, located 107 kilometres from Georgetown. Linden's population is 30,000. Discussions with a local doctor during the first visit to implement mapping studies revealed patients with lymphoedema within the community who were currently receiving no organized care. The doctor identified a group of 15 patients known to be suffering from lymphoedema within his community served by a small local hospital (3 wards, daily medical out-patients). The principal researcher arranged to see these patients in the local hospital with a local nurse selected by the doctor.

Patients were examined and the diagnosis of lymphoedema was confirmed clinically and classified using the scheme developed by Dreyer et al., in Brazil [12]. All patients were then interviewed as to their disease history and current acute attack rates. They also were asked questions on current knowledge, attitudes and practices (KAP) and completed a Dermatology Life Quality Index (DLQI) questionnaire either on their own or with the assistance of the nurse if they were illiterate (2 patients).

The interventions subsequently undertaken in this community were:

1. Education and training of a local non-specialist nurse, who was able to offer support and advice for patients within her existing role in the hospital.
2. Individual patient education
3. Access to appropriate treatments.

After the patients had been clinically assessed and completed the DLQI questionnaire, they were individually educated on LF and given appropriate advice on how to manage their lymphoedema, and educated on the importance of hygiene, skin care and elevation, as well as simple exercises to encourage lymph drainage. Treatment was given from a formulary of antibiotics (Penicillin) if current acute attack, antiseptics (potassium permanganate) and topical creams (Bacitracin ointment and Miconazole

2%). Each patient was given a tube of topical antibacterial and anti-fungal cream if clinically indicated and a patient education leaflet [13].

It was agreed that the nurse could offer advice and support to patients as and when they needed. Furthermore, the nurse could also provide education for any further patients who presented with lymphoedema. This was within her role as a nurse in Wismar hospital and did not require any extra facilities or salary. The researcher spent approximately one hour with the nurse during which time the current knowledge of LF pathophysiology, in particular the difference between infection and disease, why many patients with lymphoedema had negative blood films for microfilaria and why DEC was not an effective treatment, was explained. Morbidity reduction measures, which emphasized the importance of hygiene and skin care were also explained and demonstrated. The nurse was given further educational material and a supply of antiseptics, antibiotics and topical antibiotic and anti-fungal creams. Patients were advised to visit the nurse in the hospital outpatients if they had acute attacks or needed help with any issues. The nurse was invited to contact the researcher at the PAHO office in Georgetown if she had any questions.

The researcher visited Wismar twice during the study period to supply topical antibiotic and anti-fungal creams as required (from the Ministry of Health pharmacy bond). Six months after the initial clinic study, the nurse attended a LF workshop for health care workers in Linden. At this point the nurse was provided with a patient video; 'Lymphatic Filariasis, Hope for a better life' (English version) produced by the Centers for Disease Control and Prevention (CDC), Atlanta. Over the course of the year, more patients attended the group, which developed by word of mouth, as a result of the intervention.

The clinic was visited approximately one year later and the patients were reassessed. The number of acute attacks during the last year was recorded as reported by the patient and the DLQI was repeated.

## Results

14 patients were initially seen who had a clinical diagnosis of lymphoedema and who completed a DLQI. 11 patients were seen approximately one year later at the follow-up visit and completed the DLQI. 3 of the initial patients were not seen on this visit as they had moved from the area, and were therefore excluded from the study (Follow up = 79%). In addition, 5 patients were seen on the follow-up visit that had begun to attend the clinic over the past year.

Of the 11 initial patients included in the study, 9 were female and 2 were male. Their ages ranged from 21–65

(mean = 47) and they were all Afro-Guyanese (reflecting the ethnic composition of the local population in Wismar). The KAP study showed that before the intervention patients had received haphazard care, including use of local remedies and care from pharmacies, private doctors and hospital clinics for acute attacks. There was very limited skin care and none of the patients were aware of the importance of hygiene.

Initial DLQI ranged from 2–18 out of 30 points (mean score = 10.9 points). Mean scores in skin patients in UK for other conditions in a study of 200 patients were around this range e.g. psoriasis: 8.9 points, atopic eczema: 12.5 points, acne: 4.3 points and controls: 0.5 points [5]. These scores confirmed the hypothesis that lymphoedema has a significant impact on patient quality of life. The initial DLQI showed only a weak relationship to lymphoedema severity as assessed by Dreyer stage of the worst affected limb (0.33 Pearson's correlation coefficient). Obviously this is only one assessment of disease severity and factors such as frequency of acute attacks could also be taken into consideration in future analysis.

The follow-up DLQI scores were the same or better for all 11 patients who had the two assessments. These DLQI scores ranged between 0–11 points (mean score = 4.1 points) and the improvement varied between 0–15 points (mean improvement 6.8 points). A paired t-test (to assess the significance of the change in DLQI values for each person) gave a value of 5.9 with 10 degrees of freedom ( $p < 0.0001$ ).

Patients also reported both a decrease in lymphoedema severity and notably in acute attack rates. In the initial visit, 10 out of the 11 patients had reported an acute attack in the preceding 6 months; however, no reports of acute attacks were made by any of the 11 patients in the 6 months preceding the follow up visit. It was not felt that other clinical outcomes could be analysed accurately in this small sample. The Dreyer stage did not change in any of the patients and limb size had not been reliably measured on the first visit but even though results were not measured objectively, patients did perceive subjective clinical improvement.

## Discussion

This study shows that in this community, with only a very limited input of time and financial resources, a change/introduction in treatment regime can have a beneficial impact on patients with lymphoedema within a year. This intervention used the existing services within the community and gave them the necessary information enabling them to put into place more informed treatment. The intervention was easy to implement and required very limited follow up. This is valuable investment for a chronic

condition, which is permanent once established. However, follow up is essential to see if the effect continues over time.

It was felt from this preliminary experience in Guyana that the DLQI was an appropriate tool to assess how limb lymphoedema affected patient quality of life and in particular to monitor an intervention that concentrated on skin care treatment. A study involving larger numbers of patients could assess in greater detail which features of life quality relate specifically to lymphoedema patients, and how this tool can be used along side other life quality measures.

There are a number of reasons why this intervention could have improved quality of life (as measured by the DLQI). In discussion with the patients and the nurse, likely contributing factors raised were reduced clinical severity (in particular a reduction in acute attacks) leading to an increased ability to work and perform daily functions. Other factors which were stated included the empowerment associated with an understanding of the condition and the ability to manage it individually. Also cited as important were the support from the clinic, the nomination of a clear focal point (the designated nurse) in the hospital, the ability to meet with other patients and the networks that were formed in the community.

Interestingly, the DLQI scores in the 5 new patients were not as high as the initial group. This may reflect the fact that the improvements in the quality of service, as well as the establishment of the patient support group, benefited new patients as well.

As this study was designed to provide the entire community with access to treatment there were no controls and therefore could be no estimation of the extent of a placebo effect.

Further work on larger samples and more in-depth investigations of the degree, duration and cost of alternative approaches are needed to identify which of these factors had the greatest effect.

The nurse was non-specialist but gained confidence from her work in this area. She felt extremely positive about the effect she was able to have on patients and the autonomy she felt. She only contacted the PAHO office with requests for further supplies of topical antibacterial and anti-fungal creams and did not have any clinical questions that she felt could not be answered by the educational material she was provided with. She has been able to educate other health workers, which raises the probability of sustainability of the intervention.

## Conclusions

A minimal amount of intervention in this small sample population has resulted in an improvement in patient quality of life and ability to function within their community. This study shows that low cost interventions, which provide an initial centre for patient treatment and education on disease management, can have a significant beneficial impact on outcomes.

## List of Abbreviations used

PAHO: Pan American Health Organization

DLQI: Dermatology Life Quality Index

KAPB: Knowledge Attitudes Practices and Behavior

## Competing interests

None declared.

## Authors' contributions

TM conducted the survey, provided education and treatments for the patients, educated and provided educational materials for the nurse and drafted the manuscript.

## Additional material

### Additional File 1

*Dermatology Life Quality Index*

Click here for file

[<http://www.biomedcentral.com/content/supplementary/1475-2883-2-1-S1.doc>]

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