

ORIGINAL RESEARCH

“Effectiveness of Home Based Care Training Programme on QOL of Patients with filarial lymphedema of lower limb in selected rural areas of Khordha district, Odisha”**¹Divya Sethi, ²Shyama Devi**¹Assistant Professor, Faculty of Nursing, Desh Bhagat University, Mandi Gobindgarh, Punjab, India²Assistant Professor, Community Health Nursing, College of Nursing, AIIMS, Bhubaneswar, Odisha, India**Correspondence:**

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Abstract**Background:** Lymphatic filariasis is the second common cause of physical disability. Lymphedema has a negative impact on the quality of life of patients.**Objectives:** To assess the effectiveness of home based care training program (HBCTP) on quality of life (QOL) of patients with filariasis.**Methods and Material:** One group pre test post test design study was conducted in two villages of Khordha district during November 2019-January 2020. Total enumerative sampling was used to recruit 44 subjects. Pre test QOL was assessed at baseline followed by individual sessions of HBCTP. Subjects followed the steps of home based care for 2 months after which post test QOL was assessed.**Results:** A significant difference was found between the pre and post LFSQQ scores ($p < 0.001$). QOL was found significantly associated with age ($p = 0.004$), marital status ($p = 0.034$), duration of swelling ($p = 0.003$) and grade of lymphedema ($p = 0.011$).**Interpretation and Conclusion:** This study supports the need for home based care to improve the QOL of patients with filarial lymphedema**Key-words:** LFSQQ, Quality of life, Home-based care, Filarial Lymphedema, Lower Limb**Key Messages:** Study concluded that HBCTP showed significant changes in improving the QOL of the patients and supports the need for such programs in integration within primary care settings to improve QOL of the patients.**Introduction**

Lymphatic filariasis (LF) is the second most common cause of physical disability.¹ There are over 120 million people who were infected with the disease out of which 40 million disfigured and incapacitated by the disease.² The advanced stage of lymphedema is a painful and profoundly disfiguring problem. The disease affects all the domains of the individual including the physical, mental and social in a different way. Physical disabilities lead to distorted mental and social conditions.³ Individuals suffering from chronic lymphedema faced many psychological problems like gloominess, nervousness, the terror of lymphedema and professed a major problem affecting their lives. Sometimes people affected with filarial lymphedema may have suicidal intentions.

A minimal amount of intervention in terms of home based care training programme (HBCTP) provides an early center for the management of disease.⁴ Low cost home based self-care protocol using locally available treatment modalities has been developed in a study conducted in India.⁵ The aim of HBCTP is to reduce or halt the progression of swelling and improve QOL of patients. Although some of these interventions were done with the help of conducting camps or in special clinics but however, no studies are found where the training had been provided to the patients individually door to door by a community health nurse.

Materials and Methods

This study was a one group pre test post test design done in Orissa from November 2019 to January 2020. The study was approved by Institute Ethical Committee. Permission was taken from Medical Superintendent of CHC of the particular villages.

Patients with filarial lymphedema of lower limb residing in the Andharua and Jagannath Prasad village, District Khordha were included in the study who had grade two to seven according to Dreyer system of grading lymphedema, diagnosed and registered under health centres.⁶

The villages were chosen based on familiarity with the study setting. Total enumerative sampling was done to recruit 44 patients. Data collection form was designed to collect socio demographic and disease profile details. QOL was assessed by using Lymphatic Filariasis Specific Quality of life Questionnaire (LFSQQ).^{7,8} The content validity of the tools was done and translated from English to Odia language and back translated from Odia to English.

After obtaining informed written consent in Odia, data was collected from subjects on socio demographic and disease characteristics and baseline assessment of QOL was done. The intervention module was developed on the basis of World Health Organization. Training module on community home-based prevention of disability due to LF, Lymphoedema staff manual: treatment and prevention of problems associated with lymphatic filariasis, suggestions of community physicians, plastic surgery specialist and community health nurses.^{9,10} The module included drying and washing of limb, prevention and care of entry lesions, light oil massage, elevation of the limb, exercise, wearing appropriate footwear and management of ADL attack. Flash cards were developed in English and then translated in Odia. Checklist was given to the patients to adhere to the intervention.

Daily 4-5 patients were taken for pre-test followed by HBCTP. Interview method was used to collect data. The whole process including pre test and intervention took 1 hour to complete for one subject. The steps of home based care were discussed using flash cards and then demonstrated to the subjects. Return demonstration was taken to ensure that they follow the steps correctly. The intervention includes 2 follow up visits to encourage and enquire the subjects about the daily performance of home based care. The first follow up was done after 15 days and the second follow up was done after one month of the training intervention. Post-test was done after 2 months of HBCTP. After the entry of data in excels spreadsheet, it was uploaded in SPSS version 20. Normality of the data was analyzed by using Shapiro Wilk test.

Results

Data presented in table 1, shows that the mean age of subjects is 58.16 with standard deviation of 11.01. Data presented in table 2, shows that the mean duration of swelling of is 20.25 with standard deviation of 12.01. Figure 1, shows that majority (31.1%) of the subjects had grade five lymphedema, 28.9% had grade three lymphedema, 24.4% had grade two lymphedema, 8.9% had grade four lymphedema and 4.4% had grade six lymphedema. Data presented in table 3, shows that the difference in median QOL scores between the pre-test and post-test is statistically significant ($p < 0.001^*$). Hence, the intervention provided was effective in improving QOL of patients with filarial lymphedema of lower limb.

Data presented in table 4, shows that the difference between pre-test and post test score was found statistically significant for all the domains of LFSQQ at $p < 0.001^*$ which shows that QOL increased in all the domains. The Data presented in table 5, shows that the association between the QOL score with age is negatively correlated ($\rho = -0.43$, $p = 0.004^*$) which shows that QOL decreases with age. The association between the quality of life score with marital status ($z = 2.11$, $p = 0.034^*$) is found to be statistically significant and shows QOL is better for subjects who were married as compared to widowed subjects.

Data presented in table 6 shows that the association between the QOL score with the duration of swelling is negatively correlated ($\rho = -0.436$, $p = 0.003^*$) which shows that QOL decreases with duration of swelling. The association between the quality of life score with grade of lymphedema ($\chi^2 = 13.026$, $p = 0.011^*$) is found to be statistically significant and shows QOL is better for the subjects with lower grade of lymphedema than the higher grade.

Discussion

Discussion related to the effectiveness of home based care training programme on quality of life of subjects

Results showed a significant overall improvement in LFSQQ scores and the domain specific QOL scores in mobility, self-care, usual activity, disease burden, pain/discomfort, psychological health and social participation significantly improved (p -value $< 0.001^*$). While in a previous study, each domain's QOL in mobility, self-care, usual activity, pain and discomfort and social relationship improved significantly (p -value < 0.01) but the domain of psychological health showed no significant change.¹¹ As there was no previous similar intervention applied for the patients in the selected area, subjects might be interested to perform home based care. The novelty effect can be a factor in getting the positive results for the present study.

Least score in the present study was seen in disease burden domain. The highest score is observed in psychological health domain. Whereas in a cross-sectional study conducted on 66 patients, the least domain-specific score was observed in the mobility domain.¹² The scores of disease burden is higher may be because patients take physical problems more seriously such as large limb size, pain, redness, swelling and reports it appropriately. The psychological status of the subjects was good as the patients were suffering from the disease for many years, so they have adapted to the conditions. They don't even face any stigma. The area is endemic for the disease and everyone is aware about the problem. The maximum improvement of scores after intervention was seen in the disease burden domain. Maybe the components of home based care were better helpful in managing the physical problems like itching, wounds and foul odour. During follow up visits, it was observed that out of all components of home based care, regular washing of limb is practiced by maximum subjects as it is a routine practice among patients. This is a similar finding seen in a previous study done in Nepal which states that regular practices for foot care except washing of limb were predominantly lacking.¹³ The component which is least adhered to is wearing appropriate footwear as many of them are having larger limb size and no appropriate specially designed footwear was available. Also, subjects get adapted to this practice of not wearing footwear. Exercising and elevation of the affected limb was not followed regularly by the subjects because the majority of the subjects were older having degeneration of joints, they might be facing the problem of stiffness of joints.

Association of QOL with socio-demographic and disease variables

Interestingly, negative correlation was found between QOL and age of the subjects. Higher the age of the subject, the poorer the QOL may be. Also there was a significant relationship between the QOL score and marital status while other factors like gender, educational status,

occupation and economic status were not associated with QOL. Having a partner can be a support for the subject which helps to maintain some of the domains like psychological health and helps in self-care activities. Similar findings were reported in a study where socio-demographic factor like gender was feebly related to QOL.¹⁴ A negative correlation was found between the QOL and duration of swelling which states that the more the duration of swelling, the lesser is the QOL score. With more duration of swelling, the limb size might have increased which will further cause several day today problems like problem in mobility, usual activities and selfcare. Also, QOL was significantly associated with grade of lymphedema. In the present study findings, subjects with grade 6 lymphedema had the worst QOL scores as the progression of lymphedema is accompanied with the problems like bacterial entry points, presence of knobs, skin folds, foul odour, mossy foot and large limb size. Hence concluded that HBCTP showed significant changes in improving the QOL of the patients and supports the need for such programs in integration within primary care settings to improve QOL of the patients.

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