Quality of Life of Filarial Lymphoedema Patients in a Coastal Area of Alappuzha District, Kerala

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Abstract
Alappuzha district in Kerala is an endemic area for Lymphatic Filariasis. Since 2006 self help groups for filarial lymphedema patients were initiated with the joint efforts from the Dept of Community Medicine, NGOs and the National Filarasis Control Unit, Alappuzha. They are working for the well being and improvement of filarial lymphedema patients. A cross sectional study was conducted to estimate the quality of life of filarial lymphoedema patients in a coastal area of Alappuzha district. Various clinics were organized at the subcentre level in Mararikulam South Panchayat which is a rural coastal area in Alappuzha. Data was collected using LYMQL questionare which contains four domains— Function, Appearance, Symptoms, Mood. In each domain a score of 80 % or more was considered good. The overall score was divided into tertiles, those in the lower tertile was presumed to have good quality of life and middle and upper tertiles was considered as average and poor quality of life. A total of 56 patients were obtained. Of whom 57.1%were females. In the functional domain only 12.5% had good quality of life whereas other domains such as appearance, symptoms, mood ;92.9% ,75% ,51.8% had good quality of life respectively. Overall 8.9% had good quality of life, 82.1%had average quality of life and 8.9 % had poor quality of life.

Keywords: Quality of life , filarial lymph edema and self help groups.

INTRODUCTION
Lymphatic filariasis is one of the oldest and most debilitating neglected tropical disease. An estimated 120 million people in 81 countries are infected currently, and an estimated. 1.34 billion live in areas where filariasis is endemic and are at risk of infection. Approximately 40 million people suffer from the stigmatizing and disabling clinical manifestations of the disease, including 15 million who have lymphoedema¹. According to the World Health Organization, India, Indonesia, Nigeria and Bangladesh alone contribute about 70% of the infection worldwide². Fifteen percent of India’s filariasis patients live in Kerala; among this significant number is contributed by Alappuzha district which is an endemic area for Lymphatic Filariasis³. Since 2006 self help groups for filarial lymphedema patients were initiated with the joint efforts from department of Community Medicine—Govt. T.D Medical College, Non Governmental
Organizations and the National Filariasis Control Unit Alappuzha.
Although filariasis does not cause immediate mortality, the associated severe morbidity has resulted in it being recognized as the second leading cause of disability worldwide. This chronic disease is debilitating leading to restriction in the duration and capacity to works, changes in activity pattern, psychological and social disability which in turn affects their quality of life. The year 2010 marks the halfway point towards the projected goal of eliminating the disease by 2020; The two main goals of the global programme to eliminate lymphatic filariasis are to interrupt transmission of infection and to alleviate and prevent the suffering and disability caused by this disease and thus improving their quality of life.

The first step to achieve the above said second goal is to assess the existing pattern of these patients in the community. With this background this study wish to assess the quality of life of lymphedema patients in an area where this disease is endemic and self-help groups are working for the welfare of filarial lymphedema patients.

Material and Methods
A Community based cross sectional study was done on patients attending the community based clinics organised at various subcentre in Mararikulam South Panchayath. This is a coastal village area of Alappuzha district, Kerala. Permission from HOD and Professor department of Community Medicine and Administrative Medical Officer of Chettikadu Rural Health Training Centre under which these sub-centres are located were obtained. Study period was six months (January 2015 to June 2015). Informed consent from the patients was obtained. All the lymphatic filarial patients attended the clinics were included in this study. Thus from Chettikadu main centre -8 patients; Poonkkavu subcentre -32 patients; Cheriyapozhi subcentre -16 patients were obtained. The total number of the responders were 56. Interviewer administered, self-prepared questionnaire on general profile of the patients and LYMQOL questionnaire on Quality Of Life Of Lymphoedema patients were used to collect the data. LYMQOL questionnaire has total 21 questions and four domains such as Function, Appearance, symptoms, mood. After collecting the data, clinical examination was done and taught morbidity management for the needed patients.

Data was entered in Microsoft Excel and analyzed using SPSS software 16.0 version. Each item in the four domain of LYMQOL questionnaire, was scored as 1- Not at all; 2- A Little; 3- Quite a bit; 4- A lot. In each domain a total score of 80 % or more was considered good. The overall score (84) was divided into tertiles, those in the lower tertiles (0- 28 ) was presumed to have good quality of life and middle (29-56) and upper (57-84) tertiles was considered as average and poor quality of life respectively. Chi square test/Fischer’s exact test was used to indentify association between depended and independent variable. Odds ratio was used to determine strength of association.

Results
A total of 56 patients were studied, of whom 57.1% were females (Fig 1). The mean age of the study subjects was 64.25 (10.8) years. In this study 44.6% subjects were within the age group of 61-70 years. Majority (73.2 %) were economically dependent. Among the study subjects 75 % were suffering from this morbidity since more than 30 years. Of the study subjects 67.9% had co-morbidity (Tab 1). Majority of our study subjects had lower limb involvement (Fig 2). 76.25 % of the study subjects were involved in self help groups (Fig 3). In the functional domain only 12.5% had good quality of life whereas other domains such as appearance, symptoms, mood; 92.9%, 75%, 51.8% had good quality of life respectively (Tab 2). Overall 8.9% had good quality of life, 82.1% had average quality of life and 8.9 % had poor quality of life (Fig 4). There was a statistically significant association
(p=0.001) between average to good quality of life and self help group involvement.

**Fig 1** Sex wise distribution of study subjects (n=56)

![Sex wise distribution of study subjects](image)

**Tab.1** General Profile of study subjects (n=56)

| General Profile          | Percentage |
|--------------------------|------------|
| Economically depended    | 73.2       |
| Presence of co-morbidity | 67.9       |
| Duration of illness      |            |
| < 30 years               | 25         |
| >30 years                | 75         |

**Fig 2** Limb involvement among the study subjects (n=56)

![Limb involvement among the study subjects](image)

**Discussion**

Quality of life is one of the important ways of predicting well being of an individual. Diseases like filariasis, which mostly results in long term morbidity rather than mortality will deteriorate the quality of life of diseased person. In this study, the mean age of the subjects was 64.25 years. Various studies reported that the prevalence of filarial lymphedema was more after the age of 30 years. Most of the study subjects were economically depended. This finding is reinforced by the WHO report, which says that chronic filarial disease has...
serious social and economic efforts\textsuperscript{1}. In the present study more than half of them had lower limb involvement. Same finding was reported by Suma TK\textsuperscript{8}. Regarding quality of life, only 12.5\% had good score in functional domain. This result is similar to the study done by RS Wijesinghe et al\textsuperscript{9}. In appearance domain 92.9\% had good score, this is mainly due to the fact that 75\% of the study subjects had lymphedema for more than 35 years. In the mood domain only 51.8\% had good quality of life. This finding is similar to the study done in Sri Lanka\textsuperscript{9}. The important feature of this study is that 91\% had to average to good quality of life and it has association with self help group involvement. Same finding was reported by Coreil J et al\textsuperscript{10}. His study reported that support groups offer a low cost, psychosocial intervention for people living with chronic diseases and disability\textsuperscript{11}. The Study has the following limitations. Since it was a camp based study where only those attended the camp were included, the problem of generalization occurs.

**Conclusion**

Majority of the persons with lymph edema had average to good quality of life. Involvement of self help groups was found to have significant association with average to good quality of life.

**Source of Funding –** Nil

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