

Disability Related to Self - care management among patients with Chronic Lymphatic filariasis in Kerala, India

Muttappallymyalil J¹, Marickar YMF², Elizabeth KE³, Sreedharan J⁴

¹ Professor , Department of Community Medicine, Gulf Medical University, Ajman, UAE

² Professor, Mount Zion Medical College, Adoor, Kerala, India

³ Professor, Department of Pediatrics, Govt. Medical College, Trivandrum, Kerala, India

⁴Professor, Statistical Support Facility, Gulf Medical University, Ajman, UAE.

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Corresponding Author

Dr. Jayakumary Muttappallymyalil
Professor
Department of Community Medicine
Gulf medical university, Ajman, UAE
E-mail:drjayakumary@gmail.com

Abstract

Background

Disability in self-care is a part of physical domain and is described as the inability to withstand bodily disruptions in normal functional performance. This study was conducted to determine the pattern of self-care management in patients with chronic lymphatic filariasis and to determine the disability in self-care on the basis of gender, duration of disease and stage of the disease in Kerala.

Materials and Methods

This cross-sectional study was conducted from 2008 to 2009 among individuals suffering from chronic lymphatic filariasis in Kannur District, Kerala State, India. 200 individuals with chronic lymphatic filariasis participated in this research. An interviewer-administered questionnaire, which had structured closed-ended questions and semi-structured open-ended questions, was used for data collection. A door-to-door survey was conducted to recruit the required sample size. Data analysed using SPSS version 21.

Results

In the present study 200 individuals (151 females and 49 males) with chronic lymphatic filariasis were participated. The mean age observed was 58.8 years with a minimum of 25 years and a maximum of 85 years. The factors included under self-care were bathing, grooming, dressing, and bowel and bladder management. The severity of self-care management shows that more than 60% had no difficulty in any of the self-care activities. 40% reported having at least some problem in toileting. Among the total participants, 3.5% reported extreme difficulty in bathing, followed by 1% in grooming, 1% in dressing and 1% in toileting. Some degree of bowel management problems was reported by 61.5% participants, and 67.5% had bladder management

problems. Though males and females experienced bladder problems, former experienced them more. In both the groups the median score observed for bathing, grooming, dressing and toileting was 'none'. There was no statistically significant difference in the median score observed between males and females.

The leading difficulties related to self-care experienced by participants with duration of disease greater than 40 years were toileting (72.7%), bathing 39.4%, grooming 9.1%, and dressing (3.0%). Both bowel and bladder management problems were experienced by 85% of the participants having duration of disease greater than 40 years whereas 2.6% each experienced extremely severe bladder and bowel management problems. Statistically significant difference in median score was observed in bathing ($p < 0.05$), grooming ($p < 0.05$), Toileting ($p < 0.05$) and bowel management ($p < 0.05$), which shows as the duration of the disease increases; the difficulty for self-care management also increases. Maximum respondents with difficulty in toileting were in stage seven, the intensity ranged from a little to a lot. All distributions were statistically not different except for self-care related to toileting ($p < 0.05$).

Conclusion:

The prevalence of difficulty in self-care management showed variations between the genders, duration of the disease and stage of the disease.

Keywords: Lymphoedema, Filariasis, Difficulty, Self-care management.

Background

Disability related to activities of daily living is described as inability to withstand bodily disruptions to sustain normal functional performance. The physical disability may be present with varying degrees of intensities from tolerable to severe. The functional performance deficits are evaluated by assessing the restraints in activities of daily living. Activities of Daily Living components measured for functional performance includes a) Self-care: Bathing, grooming, dressing, toileting, b) Mobility: Standing, walking, stair climbing, lifting, bending, and c) Domestic : Cleaning, doing laundry, cooking, and shopping. In the present study, the physical dimensions refer to perceived bodily functions, disruptions and changes in functional status, which put a limitation to accomplish and fulfil physical role of the individual.

Statistically significant lower quality of life has been reported among participants with lymphoedema in the areas of physical, mental and social determinants¹. Wijesinghe et al. undertook a study in Colombo, Sri Lanka in which patients with lymphoedema were interviewed to study the physical disability and psychological impact associated with lymphoedema². The study concluded that lymphoedema significantly affects physical, psychological and social functioning in affected

Self care management in Chronic lymphatic filariasis individuals despite having been treated conventionally with long term Diethyl carbamazine citrate (DEC).

Richard et al. in their study among patients with lymphoedema reported that most of them had difficulty in feeding, dressing, and washing by themselves. Other difficulties reported were fetching water, walking to the market, or to the field and carrying heavy loads³. A study conducted in Sri Lanka reported that difficulty in walking, doing housework, standing, using the toilet, climbing stairs, walking uphill, drawing water from well, getting into a bus, holding the railing in a bus, sitting and lifting heavy objects are the major disabilities observed. The study also reported that the stages of lymphoedema were significantly associated with physical activities⁴.

The functional assessment helps to assess the disease status and identify the factors that make the individual not capable of performing activities of daily living independently. Assessing the disability associated with self-care will enable the policy makers to develop appropriate intervention strategies to plan for necessary care. Self-care is associated with the ability of the individual to perform daily basic activities such as bathing, grooming, and dressing, toileting, managing bowel and bladder functions. Hence, this paper describes the disability associated with self-care management in individuals with chronic lymphatic filariasis and its association with gender, duration of disease, and stage of the disease.

Materials and Methods

Research design:

A descriptive study was conducted among adults in Kannur District, Kerala state, India, with chronic lymphatic filariasis.

Study population:

This research was conducted among two hundred individuals with chronic lymphatic filariasis

Inclusion criteria:

Both male and female, above the age of 20 years with chronic lymphatic filariasis, willing to participate in the research were included.

Exclusion criteria:

People with other causes of lymphoedema and not consented to participate were excluded.

Sample size calculation:

Based on the proportion of people with disability, the sample size was estimated and approximated to 200. Participants were recruited conveniently till the required sample size was achieved.

Study settings:

This research was conducted from 2008 to 2009 at Kannur district, Kerala, India.

Study instrument and validation procedure:

The research instrument contained information relating to

activities of daily living, in addition to the socio-demographic characteristics. The variables included under self-care management were bathing, grooming, dressing, toileting, bowel management and bladder management. The intensity was measured in four levels. The content and face validation of the research instrument was done by two public health experts. Questionnaire was translated into local language and back-translated to English to assess the consistency of the questions by experts in the field of Public Health.

Ethical issues:

Ethics and Research Committees approval of Academy of Medical Sciences, Pariyaram, Kannur was sought before the start of the research. A prior written consent was obtained from all the study participants and all questions raised by the participants were clarified. The participants who did not wish to enrol in the research were given the opportunity to refuse to participate. Anonymity was maintained by not writing the name or any other information revealing the participant's identity. Before administration of the questionnaire, consent obtained from the prospective participants. A door-to-door survey was conducted to recruit the participants. The researcher administered the questionnaire to those who consented to participate. Clinical examination was done to locate the site and stage of the disease.

Data management and analysis:

Data were analysed in SPSS 21 version (IBM, Chicago, Illinois). Wilcoxon rank sum test and Kruskal Wallis one-way ANOVA were used to test the difference in the total and individuals self-care scores with gender, stage of the disease and duration of the disease. All statistical tests were performed using two-tailed tests at a 5% level of significance.

Results:

In the present study 200 individuals (151 females and 49 males) with chronic lymphatic filariasis were participated. The mean age observed was 58.8 years with a minimum of 25 years and a maximum of 85 years. The factors included under self - care were bathing, grooming, dressing toileting, bowel management and bladder management. The severity of self care management shows that more than 60% had no difficulty in any of the self care activities. 40% reported having at least some problem in toileting. Among the total participants, 3.5% reported extreme difficulty in bathing, followed by 1% in grooming, 1% in dressing and 1% in toileting. Details are given in Table 1.

In the total group, the highest difficulty was noted for excretory management 40%, higher among males (49%) as compared to females 37.1%. Next highest (17%) was observed for bathing difficulties, 19.1% among females and 10.2% among males. Lowest 6% and 5.5% were observed in grooming and dressing in male and female genders respectively.

Self care management in Chronic lymphatic filariasis
Table 1: Distribution of severity of the problem of Self-care among participants

| Self-care | | None | A little | A lot | Must be |
|--------------------|-----|------|----------|-------|---------|
| Bathing | No. | 166. | 23 | 4 | 7 |
| | % | 83.0 | 11.5 | 2.0 | 3.5 |
| Grooming | No. | 188 | 9 | 1 | 2 |
| | % | 94.0 | 4.5 | 0.5 | 1.0 |
| Dressing | No. | 189 | 6 | 3 | 2 |
| | % | 94.5 | 3.0 | 1.5 | 1.0 |
| Toileting | No. | 120 | 47 | 31 | 2 |
| | % | 60.0 | 23.5 | 15.5 | 1.0 |
| Bowel management | No. | 77 | 54 | 67 | 2 |
| | % | 38.5 | 27.0 | 33.5 | 1.0 |
| Bladder management | No. | 65 | 59 | 74 | 2 |
| | % | 32.5 | 29.5 | 37.0 | 1.0 |

None of the males had extreme difficulties with regard to bathing, grooming, dressing and toileting, whereas, among females it was 4.6%, 1.3%, 1.3% and 1.3% respectively. Some degree of bowel management problems was reported by 61.5% participants, and 67.5% had bladder management problems. Among males, 73.5% and females 57.6% experienced bowel management problems, whereas 81.7% of males and 62.9% of females experienced bladder management problems. Among females with bowel and bladder management problems, 1.3% each experienced extreme severity in both. Though males and females experienced bladder problems, former experienced them more. Details are given in Table 2.

There was no statistically significant difference in the median score observed between males and females. In both the groups the median score observed for bathing, grooming, dressing and toileting was 'none'. There was no statistically significant difference in the median score observed between males and females. With regard to bowel management and bladder management, the median score observed was 'a little'. Wilcoxon rank sum test was used to assess whether there is any difference in the distribution between two groups.

The disturbances in the activities of daily living among participants with various duration of disease shows that the disturbances such as toileting and bathing was reported by participants irrespective of the duration of disease. But the proportion was highest among participants with duration of disease greater than 40 years and as compared to the other two groups.

The leading difficulties related to self care experienced by participants with duration of disease greater than 40 years were toileting 72.7% bathing 39.4%, grooming 9.1%, and dressing 3.0%. Extreme severity was reported by participants with duration of disease less than 20 years in toileting 2.6%, bathing 5.3%, grooming 2.6% and dressing 2.6% respectively.

Table 2: Distribution of participants' difficulties in self-care according to severity and gender

| Self-care | Severity | Gender | | | | Total |
|--------------------|------------------|--------|------|--------|------|-------|
| | | Male | | Female | | |
| | | No. | % | No | % | |
| Bathing | None | 44 | 89.8 | 12 | 80.8 | 166 |
| | A little | 5 | 10.2 | 18 | 11.9 | 23 |
| | A lot | -- | -- | 4 | 2.6 | 4 |
| | Must be bathed | -- | -- | 7 | 4.6 | 7 |
| Grooming | None | 46 | 93.9 | 14 | 94.0 | 188 |
| | A little | 3 | 6.1 | 6 | 4.0 | 9 |
| | A lot | -- | -- | 1 | 0.7 | 1 |
| | Must be groomed | -- | -- | 2 | 1.3 | 2 |
| Dressing | None | 46 | 93.9 | 14 | 94.7 | 189 |
| | A little | 3 | 6.1 | 3 | 2.0 | 6 |
| | A lot | -- | -- | 3 | 2.0 | 3 |
| | Must be dressed | -- | -- | 2 | 1.3 | 2 |
| Toileting | None | 25 | 51.0 | 95 | 62.9 | 120 |
| | A little | 17 | 34.7 | 30 | 19.9 | 47 |
| | A lot | 7 | 14.3 | 24 | 15.9 | 31 |
| | Used bed pan | -- | -- | 2 | 1.3 | 2 |
| Bowel management | None | 13 | 26.5 | 64 | 42.4 | 77 |
| | A little | 22 | 44.9 | 32 | 21.2 | 54 |
| | A lot | 14 | 28.6 | 53 | 35.1 | 67 |
| | Does not control | -- | -- | 2 | 1.3 | 2 |
| Bladder Management | None | 9 | 18.4 | 56 | 37.1 | 65 |
| | A little | 21 | 42.9 | 38 | 25.2 | 59 |
| | A lot | 19 | 38.8 | 55 | 36.4 | 74 |
| | Has no control | -- | -- | 2 | 1.3 | 2 |

None of the participants with duration of disease between 20-40 years reported extreme severity of self care. 61.5% had some degree of bowel management problems and 67.5% had bladder management problems. Both bowel and bladder management problems were experienced by 85% of the participants having duration of disease greater than 40 years whereas 2.6% each experienced extremely severe bladder and bowel management problems. Details are given in Table 3.

The median score difference in the distribution of items related to self-care according to the duration of disease was assessed. The median score observed was 'none' for items bathing and grooming whereas in the case of dressing and toileting the median score was 'a little' among those patients with duration of disease more than 40 years whereas as those with less than 40 years the median score of the same items were 'none'. In the case of bowel and bladder

Self care management in Chronic lymphatic filariasis management, the median score in all the groups was 1 (a little). Statistically significant difference in median score was observed in bathing ($p<0.05$), grooming ($p<0.05$), Toileting ($p<0.05$) and bowel management ($p<0.05$), which shows as the duration of the disease increases; the difficulty for self care management also increases.

Table 3: Distribution of participants' difficulties in self care according to severity and duration of the disease

| Self-care | Severity | Duration of disease | | | | | | Total |
|--------------------|------------------|---------------------|------|-------------|------|-----------|------|-------|
| | | <=20 years | | 21-40 years | | 40+ years | | |
| | | No | % | No | % | No | % | |
| Bathing | None | 63 | 82.9 | 83 | 91.2 | 20 | 60.6 | 166 |
| | A little | 6 | 7.9 | 7 | 7.7 | 10 | 30.3 | 23 |
| | A lot | 3 | 3.9 | 1 | 1.1 | -- | -- | 4 |
| | Must be bathed | 4 | 5.3 | -- | -- | 3 | 9.1 | 7 |
| Grooming | None | 68 | 89.5 | 90 | 98.9 | 30 | 90.9 | 188 |
| | A little | 6 | 7.9 | -- | -- | 3 | 9.1 | 9 |
| | A lot | -- | -- | 1 | 1.1 | -- | -- | 1 |
| | Must be groomed | 2 | 2.6 | -- | -- | -- | -- | 2 |
| Dressing | None | 69 | 90.8 | 88 | 96.7 | 32 | 97.0 | 189 |
| | A little | 5 | 6.6 | -- | -- | 1 | 3.0 | 6 |
| | A lot | -- | -- | 3 | 3.3 | -- | -- | 3 |
| | Must be dressed | 2 | 2.6 | -- | -- | -- | -- | 2 |
| Toileting | None | 55 | 72.4 | 56 | 61.5 | 9 | 27.3 | 120 |
| | A little | 12 | 15.8 | 18 | 19.8 | 17 | 51.5 | 47 |
| | A lot | 7 | 9.2 | 17 | 18.7 | 7 | 21.2 | 31 |
| | Used bed pan | 2 | 2.6 | -- | -- | -- | -- | 2 |
| Bowel management | None | 36 | 47.4 | 33 | 36.3 | 8 | 24.2 | 77 |
| | A little | 21 | 27.6 | 23 | 25.3 | 10 | 30.3 | 54 |
| | A lot | 17 | 22.4 | 35 | 38.5 | 15 | 45.5 | 67 |
| | Does not control | 2 | 2.6 | -- | -- | -- | -- | 2 |
| Bladder management | None | 30 | 39.5 | 30 | 33.0 | 5 | 15.2 | 65 |
| | A little | 20 | 26.3 | 26 | 28.6 | 13 | 39.4 | 59 |
| | A lot | 24 | 31.6 | 35 | 38.5 | 15 | 45.5 | 74 |
| | Does not control | 2 | 2.6 | -- | -- | -- | -- | 2 |

Difficulty to perform bathing was observed among 17% of the respondents in different stages of the disease, and the intensity varied from 'a little' to 'must be' bathed. The difficulty in bathing was extreme in 6.3% of the respondents in stage seven and 4.8% in stage six respectively. Grooming was difficult for 6% of the participants with different stages of the disease and the intensity varied from 'a little' to 'must be' groomed. 2.4% of the participants reported that they must be dressed and this difficulty was more in stage 4 disease. Maximum respondents with difficulty in toileting

were in stage seven, the intensity ranged from a little to a lot. Among participants with difficulty in toileting, 2.4% use bed pan for toileting and they were in stage four. Details are given in Table 4.

Table 4: Distribution of participants' difficulties in self care according to the stage of the disease

| Self care | Severity | Stage of the disease | | | | | | | | Total |
|--------------------|------------------|----------------------|------|-----|-------|-----|------|-----|------|-------|
| | | 4 | | 5 | | 6 | | 7 | | |
| | | No. | % | No. | % | No. | % | No. | % | |
| Bathing | None | 70 | 84.3 | 17 | 100.0 | 43 | 82.7 | 36 | 75.0 | 166 |
| | A little | 6 | 7.2 | -- | -- | 8 | 15.4 | 9 | 18.8 | 23 |
| | A lot | 3 | 3.6 | -- | -- | 1 | 1.9 | -- | -- | 4 |
| | Must be bathed | 4 | 4.8 | -- | -- | -- | -- | 3 | 6.3 | 7 |
| Grooming | None | 75 | 90.4 | 17 | 100.0 | 51 | 98.1 | 45 | 93.8 | 188 |
| | A little | 6 | 7.2 | -- | -- | -- | -- | 3 | 6.3 | 9 |
| | A lot | -- | -- | -- | -- | 1 | 1.9 | -- | -- | 1 |
| | Must be groomed | 2 | 2.4 | -- | -- | -- | -- | -- | -- | 2 |
| Dressing | None | 76 | 91.6 | 17 | 100.0 | 49 | 94.2 | 47 | 97.9 | 189 |
| | A little | 5 | 6.0 | -- | -- | -- | -- | 1 | 2.1 | 6 |
| | A lot | -- | -- | -- | -- | 3 | 5.8 | -- | -- | 3 |
| | Must be dressed | 2 | 2.4 | -- | -- | -- | -- | -- | -- | 2 |
| Toileting | None | 60 | 72.3 | 11 | 64.7 | 28 | 53.8 | 21 | 43.8 | 120 |
| | A little | 13 | 15.7 | 4 | 23.5 | 11 | 21.2 | 19 | 39.6 | 47 |
| | A lot | 8 | 9.6 | 2 | 11.8 | 13 | 25.0 | 8 | 16.7 | 31 |
| | Used bed pan | 2 | 2.4 | -- | -- | -- | -- | -- | -- | 2 |
| Bowel management | None | 23 | 27.7 | 5 | 29.4 | 23 | 44.2 | 26 | 54.2 | 77 |
| | A little | 24 | 28.9 | 6 | 35.3 | 18 | 34.6 | 6 | 12.5 | 54 |
| | A lot | 34 | 41.0 | 6 | 35.3 | 11 | 21.2 | 16 | 33.3 | 67 |
| | Does not control | 2 | 2.4 | -- | -- | -- | -- | -- | -- | 2 |
| Bladder management | None | 15 | 18.1 | 5 | 29.4 | 21 | 40.4 | 24 | 50.0 | 65 |
| | A little | 27 | 32.5 | 6 | 35.3 | 18 | 34.6 | 8 | 16.7 | 74 |
| | A lot | 39 | 47.0 | 6 | 35.3 | 13 | 25.0 | 16 | 33.3 | 74 |
| | Does not control | 2 | 2.4 | -- | -- | -- | -- | -- | -- | 2 |

With regard to self-care, score zero was given for no difficulty and 3 was given to extreme difficulty. The median observed was zero (no difficulty), in all items except for toileting in participants with stage 7 disease. All distributions were statistically not different except for self-care related to toileting ($p < 0.05$). There was no statistically significant difference in the distribution observed with regard to stage of the disease and bowel, bladder management.

Self care management in Chronic lymphatic filariasis

Discussion

Difficulties in self-care

Individuals with chronic lymphatic filariasis especially with lymphoedema may experience difficulty in managing their day-to-day basic activities and these are related to the human needs of self-care. Shenoy et al. and Perera et al. reported the difficulties experienced by the patients in the physical domain in the later stages of lymphoedema and in individuals who had developed hydrocoele. They reported that these reduced the ability to walk, stand and sit for long periods of time and the ability to lift heavy weight^{5,6}. With regard to travelling, about 67% of the patients reported that they found it difficult to travel by bus, cycle or even walk⁷. The loss of mobility is one of the major factors preventing people from participating in domestic activities and performing in other major work roles⁸⁻¹⁰. Tyrell et al. compared the quality of life of individuals with and without chronic filariasis and they observed that among patients, chronic filarial disability related to mobility was more compared to people without chronic filariasis¹¹. Among the participants with chronic filariasis, 20% expressed their inability to dress self and 24% reported their disability to get into and out of bed, 26% reported the inability to walk outside the house and 32% reported the inability in walking inside the house¹¹. The present study observed that less than 40% the patients suffer from some type of disability with regard to self-care.

Gender variation, duration along with stage progression of Chronic Lymphatic filariasis and difficulties in safe care

None of the male patients reported extreme difficulty related to the personal care. But the median score for personal care was almost equal in both males and females. As the duration of the disease increased the disability related to personal care also increased. Also the disability related to personal care depends on the stage of the disease.

Coreil et al. reported that those with acute manifestations of lymphatic filariasis depended on other family members for their routine needs such as dressing, bathing and toileting⁸. Coreil et al. reported that acute attacks made individuals dependent on their family members for assistance with the simplest of daily activities of living such as dressing, bathing and toileting⁸. Such a situation causes a role reversal where parents become dependent on their children¹². In the present study all the difficulties were more among patients with larger duration of the disease.

As stage increased, the severity also increased. Available literature shows that no published studies regarding the difficulties in bowel and bladder management of patients with filariasis. The present study looked into these two aspects also. This study observed that these two difficulties were in similar level among both male and female participants. The difficulty was more among participants with duration of the disease greater than 40 years. The

stage of the disease will affect the bowel and bladder management.

Conclusion:

The prevalence of difficulty in self-care management showed variations between the two genders. With regard to the duration of the disease, the difficulty of self-care management increased as the duration of the disease increased especially bathing, grooming, toileting and in bowel management. There was no statistically significant difference in the distribution observed with regard to stage of the disease and self-care management except self-care related to toileting.

Author's contribution

JM concept developed, designed the study, acquired the data, conducted literature review, interpreted the results, and drafted the manuscript. YMFM interpreted the results, edited and reviewed the manuscript. EKE edited and reviewed the manuscript. JS participated in the designing of the study, statistical analysis, interpreted the data, and revised the manuscript. All the authors approved the final document.

Conflict of interest:

There is no conflict of interest among authors arising from the study.

Limitation of the study:

The results provided in the study are based on self-reported data and no effort was made to confirm the disability related to self-care.

What this study adds

Available literature shows that no such studies have been conducted in Kerala state, which is an endemic area for lymphatic filariasis. The results obtained from this research will add to the epidemiological information on the disability associated with chronic lymphatic filariasis and also open doors for further research in this area using a large sample.

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Self care management in Chronic lymphatic filariasis

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