

Abstract

Background: Lymphatic filariasis, a mosquito-borne parasitic disease, can lead to oedema and elephantiasis, is a major contributor to disability in the developing world. Information on the disability and psychological impact of filarial lymphoedema in the community in Sri Lanka are scarce. Morbidity control practices of the lymphoedema (FL) patients in a community setting were not assessed after their diagnosis, other than assessing in the clinic setting.

Therefore, this study was carried out to assess the disease status, health care seeking behaviour, acute adenolymphangitis (ADL) attacks, knowledge and practices related to morbidity control among patients with filarial lymphoedema in the community and compared the patients with a matched comparison group from the community for socio-demographic factors, disability, psychological distress and knowledge on filariasis.

Methods: Study had three components. Component I translated the World Health Organization Disability Assessment Schedule II (WHODAS II) in to Sinhala and validated among 180 patients with filarial lymphoedema and their comparison group (180) in the Colombo district before its application in the main study.

Component II, a community based comparative study conducted in the Colombo district, assessed the socio-economic and demographic factors, knowledge on filariasis, disability and psychological distress between 200 patients with filarial lymphoedema (cases) and comparison group (200), and assessed the disease status, health care seeking behaviour, ADL attacks, knowledge and practices related to morbidity control among lymphoedema patients.

Component III assessed the impact of the filarial lymphoedema and described the coping mechanisms adopted by patients using a qualitative research method.

Conclusions: WHODAS II showed judgmental validity, construct validity, convergent validity, discriminant validity, internal consistency and test retest reliability.

Mean age of the cases was 57.4 years (SD= 12.35years), a majority were females (83.5%) and currently married (55%). Patients with unilateral left lower limb lymphoedema (44.0%) were higher than unilateral right lower limb lymphoedema (39.5%) and bilateral lymphoedema (16.5%). A majority (57.5%) had Grade III and IV lymphoedema while 37.0% had grade II lymphoedema.

Even though, all the cases had ever attended at least one allopathic doctor and treated with DEC, only 57% of cases had ever attended a filariasis clinic and only 37% out of cases had visited the filariasis clinics during last 5 years after the commencement of educating the morbidity control measures in the year 2003.

A majority of the patients (96%) had done Filarial Antibody Test (FAT) which is of little use for the diagnosis of clinical filariasis in endemic areas.

ADL attacks and repeated ADL attacks aggravate the swelling leading to elephantiasis. About 80% of cases reported of ever having ADL attacks, 35.0% had experienced ADL attacks during the last one year, while 17% had experienced ADL attacks during the past three months. A majority had warmed their limbs (80.0%) during ADL attacks; which is an incorrect practice. ADL attacks during last one year, was significantly higher among those with: lower educational categories, lower income categories ($p = 0.007$), Grade III and Grade IV lymphoedema ($p=0.000$), not wearing footwear ($p=0.000$), not practicing washing as a morbidity control measure ($p=0.001$), and not attending the filariasis clinic during last 5 years ($p=0.015$).

A majority of the cases had heard of the morbidity control measures: wearing footwear (58.5%), elevation on swollen limb (66.0%), bandaging (59.5%) and prevention of trauma to swollen areas (69.0%). Only 39.0% have heard of washing and 31% on exercising the swollen limbs.

Filariasis clinics of the AFC and regional filariasis clinics were the places specified by majority for obtaining messages on each morbidity control measure. All cases had received messages on washing and approximately 92% on exercising of the swollen limb from these

clinics. Of the practices of morbidity control measures among FL patients, 87% used footwear with 90.8% using out doors only, 29% had practiced washing with only 24% practicing washing at correct time, either at morning and night or at night only, 53.5% practiced elevation of swollen limb, 15% exercised the swollen limb and 57% ever bandaged the swollen limb with a majority (68.4%) applying the bandages at the correct time in the morning soon after waking up.

Disability scores of each domain and total WHODAS II were significantly higher among cases than the comparison group ($p=0.000$).

Prevalence of psychological distress among cases (50.5%) was higher than the comparison group (24.5%).

The in depth interviews among cases found that there had been an impact on; education if the disease occurred at an early age of life, work, economic status, marital and sexual life and the psychological well being. Some cases were stigmatized by their families, neighbours and society. All the interviewees had psychological consequences of embarrassment over the disfigurement, sadness, loss, loneliness, distress and shame. Some were depressed and had features of self negligence. These cases have adopted several coping mechanisms to overcome problems arising from the disease status and its consequences.

Conclusions and recommendations: The study concluded that WHODAS II is a valid and reliable tool to assess disability among patients with filarial. Community Home Based Care (CHBC) services should be provided to ensure the patients practicing morbidity control measures. Measures should be taken to improve the psychological wellbeing of the FL patients, as it was shown by both qualitative and quantitative methods that they experience psychological distress. Counselling programmes should be implemented targeting the clinic attendees and those in the community.