

## **ABSTRACT**

### **Introduction**

Despite the achievement of national elimination target in Sri Lanka, leprosy continue to be a challenging issue in the Western Province which has the highest number of cases.

Disabilities and disfigurement associated with leprosy affect patient's quality of life (QOL). Identification of needs and gaps of service delivery and assessment of service utilization at clinic and field level would help to redesign the existing control activities. Identifying reasons for defaulting will be important to develop and change strategies to address the gaps in service provision for defaulters.

### **Objectives**

The study was carried out with the objective of assessing the quality of life, healthcare service provision, utilization, factors associated and underlying reasons for defaulting among adult leprosy patients in the Western Province.

### **Methods**

Different methods were adopted for data collection in achieving the objectives of the study.

Assessment of Quality of Life: A descriptive cross-sectional study was conducted to assess the QOL of 572 adult leprosy patients attending clinics in the Western Province using locally validated Sinhala version of the WHO QOL questionnaire (WHOQOLBREF). Consecutive sampling method was applied and data was collected using an interviewer administered questionnaires (IAQ).

Assessment of service provision at hospital clinic: Stratified random sampling method was used to select 12 dermatology clinics and service provision was assessed by a pretested checklist. Preliminary checklist was developed by referring to the validated checklist by Theunuwara (2013), literature search and getting supervisor's feedback. Final checklist was developed by using Modified Delphi technique with a group of experts. Data were gathered by observations and interviewing different categories of hospital staff.

Assessment of service provision at MOH office: Stratified random sampling method was used to select 22 MOH offices and pretested checklist was used to assess the service provision. Preliminary checklist was developed by doing literature search with supervisor's feedback. Modified Delphi technique was used to develop the final check list with group of experts. Medical Officer of Health and Supervising Public Health Inspectors in the MOH office were interviewed to gather data.

Utilization of government healthcare services: A descriptive cross sectional study was conducted to assess the utilization of government healthcare services by 672 adult leprosy patients in the Western Province. Paucibacillary patients diagnosed at least 6 months and above, and Multibacillary patients diagnosed at least 12 months and above were selected by consecutive sampling method. An IAQ was used to collect data on service utilization at both clinic and field level.

Factors associated with defaulting: A hospital based unmatched case control study was conducted among 98 cases and 294 controls to determine the factors associated with defaulting. Cases were default leprosy patients (including true defaulters and defaulters who have restarted treatment) and controls were patients on regular treatment. Defaulters were selected using the clinic leprosy register and all eligible cases were recruited for the study since the number of defaulters was limited. For one case three controls were selected by consecutive sampling method. Data collection was carried out at household and clinic level. Pretested IAQ was used to collect data.

Underlying reasons for defaulting: A qualitative study was conducted with semi structured in-depth interviews to explore the underlying reasons for defaulting among 18 defaulters and 10 patients on regular treatments. Purposive sampling method was applied and data collection was carried out at household and clinic level. Audio recordings of the interviews were later converted to written records.

Ethical Clearance was obtained from the ethical review committee, Faculty of Medicine, North Colombo Medical Faculty. Simple descriptive statistics, T test, Chi square test, bivariate analysis and Multi variate analysis were used in analysis.

## **Results**

Overall QOL had a mean score of 3.4 (SD=0.8) with overall general health having a mean of 3.6 (SD=2.2). Mean scores of domains of WHOQOLBREF included; physical 69.8(SD=17.1), psychological 68.2(SD=16.6), social relationships 55.1(SD=25.0), environment 64(SD=18.3) by the study sample. In socio demographic factors, a higher QOL was observed in patients <60 years, male sex, passed O/L or higher, and who are currently employed with an income of Rs. 40,000 or more, and living in a permanent house. Higher QOL was observed in patients without disability and those who can perform their daily activities alone.

Service provision for leprosy patients was satisfactory in all hospital categories in the Western Province. Highest total mean waiting time of 344 minutes (SD=47.2) was in the Colombo South Teaching Hospital (CSTH) and a lowest of 50 minutes (SD=11.2) in the Central Leprosy Clinic (CLC).

In 2017, Colombo district had the highest number of leprosy cases reported (157 cases). MOH areas Moratuwa (88 cases), Negombo (31 cases) and Beruwala (43 cases) had highest number of cases in the Colombo, Gampaha and Kalutara districts respectively. Seven out of 22 MOH areas had poor record keeping. In the Moratuwa MOH area 55% (48 cases) were investigated after 14 days. In the Koralawella PHI area (belonging to Moratuwa MOH area), contact tracing and health education was given only to 8 (48%) patients.

Percentage of clinic utilization by adult leprosy patients in the Western province was 87.8%. There was a mean patient related delay of 16.8 months, mean health care system delay of 21.2 days and mean overall delay of 17.5 months.

Services provided by MOH office for families affected with leprosy was known by 53.8% (298) of patients. Nearly half of the sample (n=356, 53%) knew that the PHI has a role to examine family members. Majority of family contacts were examined at the hospitals (n=299, 44%), one third (n=207, 30.8%) by the PHI, 6.8% (n=46) at the MOH offices. PHIs had visited 56.7% (n=401) of the patient's houses and 54% (n=363) had received health education by PHI. Examination of all family contacts for leprosy was 82% (n=552).

Following factors were identified as risk factors for defaulting in the logistic regression (LR) analysis after adjusting for confounders; age less than 60 year (adjusted OR=3.2, 95% CI:1.55-6.64, P<0.05), poor knowledge (adjusted OR=9.6, 95% CI: 4.96-18.55, p<0.001), normal treatment regime (adjusted OR=4.0, 95% CI:1.82-9.02, p<0.001), poor care giver support (adjusted OR=7.8, 95% CI:3.97-15.46, p<0.001).

Mean Quality of life domain scores were significantly reduced (P<0.05) among cases who were defaulters [physical 63.4, psychological 54.7, social relationships 41.2 and environmental 46.3] compared to controls who were non defaulters [physical 69.2, psychological 70.3, social relationships 58.8 and environmental 66.8].

Following reasons for defaulting were identified in the in depth interviews: low income, substance abuse, early disappearance of skin patches, work commitments, temporary change in the residence, physical disability, poor knowledge and attitudes, side effects of the drugs, not seeing improvement with drugs, long waiting time, unsatisfactory behavior of the health staff, poor care giver support and stigma.

**Conclusions:** QOL of leprosy patients was good in physical, psychological, environment domains and was poor in social relationships domain. Satisfactory service provision was found in all dermatology clinics in the Western Province. Apart from CLC the mean total waiting time exceeded one hour in all other hospitals. Unsatisfactory record maintenance, delay in case investigations, reduction in providing health education and contact tracing were found in MOH areas with large number of cases. Utilization of clinic services was satisfactory. A considerable patient related delay was found. Half of the patients were aware of available field services. Majority of contact screening were conducted at hospitals. After adjusting for confounders, age less than 60 year, poor knowledge, normal treatment regime and poor care giver support were found to be risk factors for leprosy defaulting.

**Recommendations:** Continuous awareness programs should be conducted for health workers and community to facilitate early identification of disease, which will reduce disabilities and improve QOL of patients. Appointment system should be introduced to reduce waiting time in clinics. Duration taken to conduct case investigations, record keeping, provision of health education for leprosy patients and contact tracing at the MOH offices need to be closely monitored by the supervising officers. Patients should be well educated from the onset to continue treatment and providing a traveling allowance for needy patients will encourage clinic attendance. Further studies should be carried out to explore the association of substance abuse and defaulting. In addition a study comparing QOL among leprosy patients and general population would give proper picture on QOL of leprosy patients.

**Keywords: Leprosy, Quality of Life, Service Provision, Utilization, Defaulting**