

## ABSTRACT

**Introduction:** End Stage Renal Disease (ESRD) is stage five or last stage of Chronic Kidney Disease (CKD). It is a well-recognized global as well as local public health problem and burden to Sri Lanka. The treatment process is highly expensive.

**Objectives:** .The aim of the study was to describe the epidemiology, cost, barriers to treatments and social support among patients with ESRD registered in the Nephrology Unit (NU), Teaching Hospital Kandy (THK).

**Methodology:** A descriptive cross sectional study was carried out to describe the epidemiology of ESRD patients attending NU, THK with 391 ESRD patients registered in the hospital using pretested interviewer administered questionnaire and data record sheet.

A descriptive follow up cost study was done for three month duration retrospectively from the date of commencement of the study to estimate hospital cost and direct household cost of ESRD patients attending NU, THK with same group of patients using data record sheets and interviewer administered questionnaire.

A qualitative study was carried out to explore barriers to treatments and social support of ESRD patients attending NU, THK with 18 ESRD patients and 3 healthcare providers conducting in-depth interviews.

**Results:** Component 1 of the study revealed that this was a male preponderance study [294 (75.2%) males and 97(24.8%) female]. Mean age was 49 years. Majority of patents belonged to the income group of Sri Lankan Rupees (LKR) 10001-25000 (n=131, 33.5%). The majority of ESRD patients (n=170, 43.5%) were diagnosed as ESRD within 0-12 months since diagnosed as CKD. The leading probable underlying etiological disease condition was diabetes (n=113, 28.9%) followed by CKDu (n=70, 17.9%), hypertension (n=68, 17.4%) and glomerulonephritis (n=32, 8.2%).

The sum of total direct fixed costs and total of apportioned indirect costs of NU, THK was LKR 21.2 million in mid-2017. The highest contribution was from staff salaries (68.21%) followed by surgical consumables (14.65%), electricity (7.36%) and maintenance (5.64%).The average patient day cost of CC, NU, THK was LKR 3752.73

in mid- 2017. The total mean monthly hospital cost was LKR 26712.95. Hemodialysis (HD) was the main cost contributor to total hospital cost (45.35%). It was followed by cost of inpatient treatment (13.28%) and hospital drug cost (12.64%). The mean monthly total hospital cost relevant to patients of Kidney Transplant (KT), post KT beyond 3 months, HD and Continuous Ambulatory Peritoneal Dialysis (CAPD) were LKR 86475, 23672, 43896 and 104478 respectively and there is a statistically significant difference between these groups.

The total monthly median household cost was LKR 2343.33 (IQR 993 – 2251). The transport cost was the highest contributor (47.1%). It was followed by expenditure for residential facilities close to the THK (20.9%) and food during transport and taking hospital treatments (16.1%). The mean monthly total household relevant to patients of KT, post KT beyond 3 months, HD and CAPD were LKR 30828, 6831, 9396 and 2605 respectively. Among ESRD patients who were on Renal Replacement Therapies (RRT), HD patients bear highest transport cost (mean= LKR 5708.08, n= 129). It was followed by post KT patients beyond 3 months (mean= LKR 2447.46, n=41) and CAPD patients (mean= LKR 1690.91, n=9).

Concerning the barriers to treatment, the highly emphasized theme was financial difficulties. It was followed by health care services related issues, difficulty in finding a donor, transport issues and lack of knowledge on disease and related matters. In social support, the highly emphasized theme was family and relations support. It was followed by health care team support, neighbors, friends and workplace support, government (non-health) support and social groups support.

**Conclusions and recommendations:** It was revealed that majority of ESRD patients were late presentations. The leading probable underlying etiological disease was diabetes (28.9%). It was followed by CKDu (17.9%) and hypertension (17.4%). There was an upward trend of CKDu compared to past studies.

Hemodialysis was the main cost contributor to the total hospital cost (45%). It was followed by in-patient treatment cost (13%), hospital drug cost (13%) and laboratory investigation cost (11%).

Transport cost was the highest contributor (47%) to the household cost followed by cost for residential facilities close to the THK (21%) and food cost during transport and taking

hospital treatment (16%).When comparing mean monthly household cost of 3 RRT modalities, the least household cost was involved with CAPD. When comparing transport cost among 3 modes of RRTs, HD patients bore the highest transport cost and CAPD patients bore the minimum transport cost.

The highest emphasized barrier to treatments was financial difficulties. It was followed by health care services related issues, difficulty in finding a donor, transport issues and lack of knowledge on disease and related matters. By and large social support of ESRD was satisfactory. It was compatible with epidemiological part of the study as well.

It is recommended to take measures to strengthening of primordial and primary prevention to control of diabetes, CKDu as well as hypertension, strengthening and expansion of screening programs to early diagnosis of CKD, Strengthening of referral system, recruitment of social workers as well as counsellors to NUs to elicit patients' grievances to find solutions and establishment of public health nurses services to the field as there is a vacuum.

**Keywords:** End Stage Renal Disease, Chronic Kidney Disease, Renal Replacement Therapy, Barriers to treatments, Social support. Hemodialysis, Kidney Transplant, Continuous Ambulatory Peritoneal Dialysis