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SYMPTOM BURDEN AND EUROQOL EQ-5D-5L UTILITY-BASED QUALITY OF LIFE FOR AUSTRALIAN PATIENTS WITH END-STAGE KIDNEY DISEASE RECEIVING RENAL SUPPORTIVE CARE. PRELIMINARY RESULTS FROM A PROSPECTIVE STATEWIDE COHORT ANALYSIS

Rachael Morton⁵, Anna Hoffman³, Elizabeth Josland³, Cecile Couchoud¹, Sheree Smith⁶, Frank Brennan², Mark Brown⁴

¹National French ESRD Registry REIN, French Agence de la Biomedicine, Paris, France, ²Palliative Care, St George Hospital, Kogarah, Australia, ³Renal Medicine, St George Hospital, Kogarah, Australia, ⁴Renal Medicine, St George Hospital and UNSW, Kogarah, Australia, ⁵NHMRC Clinical Trials Centre, University of Sydney, Sydney, Australia and ⁶School of Nursing and Midwifery, Western Sydney University, Penrith, Australia

INTRODUCTION AND AIMS: The Renal Supportive Care Service is a networked statewide service that integrates palliative care into existing renal services, funded by the New South Wales Ministry of Health. The service helps patients and their families with End Stage Kidney Disease (ESKD) to live as well as possible by better managing their symptoms and supporting them in living with advanced disease. Patients can be pre-dialysis, receiving renal replacement therapy, on a conservative (non-dialytic) pathway, or considering withdrawing from dialysis.

METHODS: Symptom burden was measured using the Integrated-Palliative care Outcome Scale symptom list - Renal (IPOS- Renal) for 17 symptoms (0–4 scale, not at all to overwhelming); quality of life was measured with the EuroQol 5 dimensions 5 levels (EQ-5D-5L) questionnaire (0–1 scale, death to full health) and visual analogue scale (0–100) at each clinic visit. Means with standard deviations (SD) and medians for IPOS-Renal and Karnofsky scores are reported. EQ-5D-5L utilities were estimated using values from the Australian population, and are presented for the overall cohort at baseline and by treatment pathway.

RESULTS: Of 1255 patients from 22 renal units, managed through the service between January 2016 and September 2017, 353 (28%) completed the EQ-5D-5L questionnaire, mean age 78 years. 49% were on a conservative (non-dialysis) pathway, 38% dialysis, 7% pre-dialysis, 3% transplant, and 3% pathway unrecorded. Considering only the maximum symptom burden values for each patient, the median IPOS-Renal score was 19 (mean 19.43, SD 9.69); median Karnofsky score 70 (mean 66.52, SD 15.15). The mean baseline EQ-5D-5L utility index was 0.45 (SD 0.39), minimum -0.60, maximum = 1.0, and the mean visual analogue scale was 59.85 (SD 21.06). The mean utility by treatment pathway was 0.49 (SD 0.36) for conservative care (n=174); 0.40 (SD 0.42) for dialysis (n=135); 0.47 (SD 0.40) pre-dialysis (n=24); 0.30 (SD 0.47) transplant (n=10); and 0.61 (0.42) for those with a pathway unrecorded (n=10). At baseline, mobility, pain, and usual activities dimensions were responsible for the greatest decrement in quality of life.

CONCLUSIONS: These data suggest that for patients with a high level of symptom burden, quality of life utilities are lower than previously reported regardless of treatment pathway. Interventions that target mobility, pain and usual activities dimensions may improve overall quality of life. These utility estimates are essential for calculating the economic benefit of new models of renal supportive care for all patients with ESKD.