

Symptom burden clusters in people with chronic kidney disease

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Introduction

The symptom burden in people with chronic kidney disease (CKD) is high. Research suggests that, on average, patients suffer from 5-8 symptoms simultaneously dependent on stage [1-3]. Management strategies that address clusters of coinciding symptoms may be more effective in improving quality of life. However, evidence to inform such strategies is limited [4].

The objectives of this analysis were to:

- (1) Describe the symptom burden of CKD patients treated in secondary care in the UK, by treatment modality
- (2) Identify symptom clusters and to what extent they differ between CKD treatment modalities

Methods

This work is part of a larger study of symptom burden and health-related quality of life in CKD patients, using data from the Transforming Participation in Chronic Kidney Disease project and the UK Renal Registry. Fourteen renal centres across England collected patient-reported symptom data captured by the POS-S (Palliative care Outcome Scale – Symptoms) Renal questionnaire [5], which assesses 17 symptoms on a 5-point scale (0=not at all, 1=slightly, 2=moderately, 3=severely, 4=overwhelmingly). A patient's total symptom score was defined as the sum of their individual symptom scores. The total number of symptoms was the number of symptoms with a score of two or more (i.e. at least moderately affected by the symptom, limiting some activity or concentration). For both objectives, we analysed data stratified by modality (pre-end stage renal disease (pre-ESRD), peritoneal dialysis (PD) haemodialysis (HD) and transplant (Tx)). For objective 2, we used principal component analysis (PCA) to investigate clustering of symptoms.

Results

3256 patients were included; 718 (22%) were pre-ESRD, 129 (4%) were on PD, 1509 (46%) on HD, and 900 (28%) on Tx. HD patients had the highest overall symptom score and the highest number of symptoms (mean (SD) 18.2 (11.6) and 6.5 (3.9), respectively), while Tx patients had the lowest (mean (SD) 11.6 (10.3) and 4.8 (3.5)). Weakness or fatigue was the most commonly reported symptom across all modalities, and was at least moderately affecting over 60% of HD and PD patients, compared to 38% of Tx patients. Other commonly reported symptoms included poor mobility (45% of all patients), difficulty sleeping (38%), and pain (37%).

For HD and Tx patients, similar clusters were seen with one relating to skin and physical discomfort, one cluster of gastrointestinal symptoms and a third cluster of more varied but co-occurring symptoms (Figure 1). For pre-ESRD patients, the skin cluster was not identified but anxiety and depression formed a separate cluster. Only two clusters were identified for PD patients, potentially due to the smaller size of this subgroup, with skin and gastrointestinal symptoms appearing together.

Conclusion

People with CKD in England, in particular those receiving HD, have a high symptom burden, characterised by both a high severity and number of co-occurring symptoms. Symptom clusters differed between pre-ESRD

patients and people on renal replacement therapy. As a next step, we will investigate the association between symptom cluster scores and quality of life. This will inform which clusters warrant future studies to develop and evaluate cluster-level symptom management strategies.