

Patient activation, symptom burden and quality of life across chronic kidney disease stages: results from a large UK cohort

Miss Winnie Magadi¹, Dr Shalini Santhakumaran¹, Dr Sabine N Van der Veer², Prof. Nicola Thomas³, Mrs Rachel Gair¹, Prof. Alice C Smith⁴

¹UK Renal Registry, Bristol, United Kingdom, ²Centre for Health Informatics, Division of Informatics, Imaging and Data Science, University of Manchester, Manchester, United Kingdom, ³School of Health and Social Care, London South Bank University, London, United Kingdom, ⁴Department of Health Sciences, University of Leicester, Leicester, United Kingdom

Introduction

Patient activation, the knowledge, skills and confidence of an individual to manage their own health, can be assessed via the Patient Activation Measure (PAM), which places respondents into one of four activation levels ranging from Level 1 (lowest) to Level 4 (highest). There is increasing evidence that in people with chronic disease, higher levels of patient activation are associated with better health outcomes. In chronic kidney disease (CKD), a few small studies have described associations between patient activation and both Health-Related Quality of Life (HRQoL) and symptom burden, but there is little evidence available from the UK CKD population. The Transforming Participation in CKD (TP-CKD) programme gathered Patient Reported Outcome Measure (PROM) data from a large UK kidney patient population, comprising non-dialysis and pre-dialysis CKD, dialysis and kidney transplant patients. This study aimed to explore the factors associated with patient activation in the TP-CKD cohort.

Method

This cross sectional study comprised of 3,325 adults (\geq aged 18) from 14 UK renal units who completed the Your Health Survey (YHS) as part of the TP-CKD programme. The YHS included the Patient Activation Measure, the POS-S Renal and the EQ-5D-5L for assessment of patient activation, symptom burden and quality of life, respectively. The survey data were linked to the UK Renal Registry (UKRR) data to obtain information on patient demographics and comorbidities.

Latent class analysis (LCA) was used to identify classes that best described the HRQoL and symptom burden data. Multinomial logistic regression analysis was used to investigate the association between patient activation and symptom burden and HRQoL separately, adjusting for age, gender, deprivation, comorbidities and treatment modality.

Results

After excluding those lacking UKRR-linked data, the final sample included 2,644 patients (mean age 61.5 years, 60.3% males, 53.3% haemodialysis patients). 25.4% were PAM level 1, 18.6% PAM level 2, 33.9% PAM level 3 and 17.7% PAM level 4.

LCA found that three classes provided a good fit to the data for HRQoL (high, medium and low quality of life) and for symptom burden (few, some and many) (Figure 1).

Results of the regression models showed that highly activated patients (PAM level 4), the odds of having a low quality of life is 4% compared to the least activated patients (PAM level 1), and the odds of having a higher quality of life increased with patient activation. A similar trend was observed for symptom burden, with patients who were highly activated having low odds (4%) of having many symptoms (Table 1).

Discussion

This is the first large UK study to demonstrate that low activation levels are associated with a higher symptom burden and reduced quality of life across the trajectory of CKD stages and treatment modalities. Identifying the factors associated with low and high activation levels indicates which patients may need extra help to manage their health, symptoms and quality of life. This overlooked topic merits more research and clinical attention to optimise resource targeting and deliver improved care quality and outcomes at lower costs.