

P119

P119 -Empowering and Supporting Self Management

Ms Rachel Gair¹, Ms Catherine Stannard, Ms Winnie Magadi¹, Dr Richard Fluck²

¹Uk Renal Registry - Renal Association, Bristol, United Kingdom, ²Royal Derby Hospital, Derby, UK

INTRODUCTION AND AIMS: Activation describes an individual's knowledge, skill and confidence in managing their own health and healthcare. It can be measured using the Patient Activation Measure (PAM1) subdivided into 4 levels of activation, 1 being the lowest and 4 the highest. Highly activated patients are more likely to adopt healthy behaviour, lower rates of hospitalisation, and higher levels of satisfaction with services, whilst those with low activation levels are more likely to attend accident and emergency, to be hospitalised or re-admitted to hospital after discharge². Understanding a person's activation levels may allow tailoring of support accordingly. This individualised approach helps to develop a patient's skills, motivation and confidence, taking into account their needs and capabilities. We measured PAM, symptom burden and quality of life in a group of people with kidney disease approaching the need for renal replacement therapy and analysed the results to highlight risk and help tailor support where most required.

METHODS: A paper copy of a health survey previously used and validated was given to outpatients attending a low clearance clinic. The survey tool consisted of (1) 5 questions on overall health (EQ-5D-5L), (2) 17 questions on symptoms (POS-S renal) and (3) 13 questions on the ability of the patient to manage their health (PAM). The EQ-5D-5L use scales from '0' representing no problems/concerns to '5' representing the highest level of severity/concern. The POS-S renal questions use scales from 0 to 4 representing increasing severity of symptoms. These were collapsed and recoded to absent or mild (0, 1), and moderate/severe/overwhelming (2, 3, 4). PAM scores were recoded into low (1,2) and high (3,4) activation.

RESULTS: Four renal units submitted baseline data on 200 patients attending a low clearance outpatient clinic. Overall 54% respondents showed low activation levels (1&2) and 43% high activation levels (3&4); for 3% a score was missing. Female respondents showed higher levels of activation (48.2%) than males (39.6%) and respondents aged 18-64 showed a higher level of activation (54.5%) compared with 37.4% in the over 65 age group. Overall 20% of all respondents disagreed/disagreed strongly that they understood what their prescribed medications do and 28% disagreed/disagreed strongly that they were able to maintain lifestyle changes, like healthy eating and exercising, even during times of stress. The presence of moderate to severe symptoms ranged greatly from 3.0% for vomiting, 26.3% for itching, 23% feeling depressed and 47.5% reported as feeling anxious and worried. Overall the five most prevalent symptoms were weakness and lack of energy (58%), poor mobility (47%), difficulty sleeping (33.8%), shortness of breath (33.8%) and drowsiness (33.3%). At least moderate impairments in mobility, usual activities, pain/discomfort, anxiety/depression and self-care were reported in 50%, 41.5%, 36.3%, 21% and 19% respectively.

CONCLUSIONS: We found that people with kidney disease approaching renal replacement therapy within a low clearance environment reported a high symptom burden and low activation levels which makes it important to capture them alongside traditional markers of care. Future studies should investigate the impact of tailoring interventions such as coaching to improve activation at this critical point in the patient pathway as they make decisions regarding treatment options and develop behaviours around self-management. Measuring patient activation supports clinicians and organisations to help patients adopt positive health behaviours and improve their management of their conditions. Further work is necessary to up-skill the workforce to enable them to tailor support to those patients at a low activation level and with a high symptom burden.

[1,2] Hibbard, J. H, et al. (2004) Health services research, 39(4p1), 1005-1026.