Developing a person-centred approach to care in a dialysis unit – the role of Patient Activation and Quality of Life measures

**Introduction and Aims**

Our understanding of what it means to be ‘person-centred’ has evolved to encompass recognition of the active roles that individuals can play as partners in their health and health care. Policy focus and emphasis has increasingly encompassed this understanding, leading to a growing interest in the training, infrastructure and incentive implications of shared decision making and self-management support. Evidence shows that improving an individual’s knowledge, skills and confidence (Patient Activation) to manage their own health and healthcare results in a better experience of care, improved clinical and Quality Of Life (QOL) outcomes and a reduction in health resource utilisation1.

Our aim was to implement and explore the initial benchmarking results of data on Patient Activation and (QOL) outcomes of haemodialysis patients in a satellite unit in England with a view to develop a more person centred approach to care.

**Method**

Through the Transforming Participation in CKD (TP-CKD) programme the unit implemented a QOL survey tool consisting 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 and a patient activation level was calculated (1 least activated, 4 most activated). The EQ-5D-5L and POS-S -renal questionnaire use scales from ‘0’ representing no problems/concerns to ‘4’ representing the highest level of severity/concern. A paper copy of the survey was given to patients by the named nurse with completed surveys returned to the Registry and scanned into the database. The results of the surveys were made available to the unit and to the patients via Patient View.

**Results**

Initial benchmarking data was submitted on 42 of 60 haemodialysis unit patients. All patients reported at least moderate impairments in mobility,(50%) self-care (26%), usual activities (52%), pain/ discomfort (48%), anxiety/ depression (14%.) The presence of at least moderate symptoms ranged greatly from 12% for vomiting and diarrhoea to 36% for restless legs, 43% for itching and 60% for weakness/lack of energy. Amongst respondents 46% had activation levels of 1and 2 whilst 54% had activation levels of 3 and 4.

**Conclusion and next steps**

The reported high burden of symptoms and relatively low activation levels of the patients surveyed makes it important to capture these measures alongside traditional clinical markers of care. These measures have been used by the named nurses in the unit to develop a person centred approach and plans are already in place to use these markers in the multi disciplinary team to focus on interventions pertinent to the individual.

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