

Patient activation and kidney disease specific knowledge in an advanced kidney care clinic

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Introduction:

Patient activation and disease knowledge are two of the key domains required to navigate the complex decision making and self-management necessary in CKD5. Whilst both patient activation and disease knowledge have been identified as important factors in advancing health outcomes there are limited data on their role in the low clearance setting.

Methods:

Patients attending a tertiary centre advanced kidney care clinic with a cohort of approximately 500 patients were invited to complete a questionnaire combining a validated patient activation measure[1] and kidney specific disease knowledge score[2]. Patients willing, but unable to complete the questionnaires were assisted by a family or staff member. All patients attending the clinic had a 1 hour first appointment focusing on education, were given an educational booklet, and were also offered a more comprehensive education afternoon. Clinic letters were addressed directly to patients and included relevant blood results including reference to the remaining kidney function.

Results:

101 completed surveys were analysed. Demographic data is shown in table 1. The distribution of results by patient activation level (range 1-4 with level 4 denoting high activation) and kidney knowledge score (max score 24) are shown in Figure 1A-B. Patient activation measure score was inversely correlated with age ($r = -0.27$, $p = 0.006$) and positively correlated with the kidney knowledge score ($r = 0.24$, $p = 0.018$). There was no correlation between activation and social deprivation (measured by indices of multiple deprivation) Kidney knowledge score did not increase with number of clinic visits (Fig 1C). Kidney knowledge was higher in patients who had attended a kidney education session. (15.29 ± 0.51 vs 12.72 ± 0.68 mean \pm SEM $p = 0.013$) (Fig 1D), patient activation measure was similar irrespective of attendance at the education session.

Analysis of specific questions in the kidney disease knowledge score revealed that only 66% of patients knew that kidneys made urine, 63% of patients knew that the kidneys were important for controlling potassium and 27% of patients could identify eGFR as a test used to measure kidney function. In contrast, 90% of patients were able to identify a modality of renal replacement therapy e.g. haemodialysis.

Discussion:

Kidney disease specific knowledge was variable, and whilst it was augmented by attendance at an education day, a large number of patients were not able to correctly identify some basic aspects of kidney function. This highlights the need to modify educational content to ensure it is appropriately targeted.

Approximately half the cohort had a low level of activation (1 or 2) suggesting limited self-management capacity. As activation is potentially modifiable[3], any interventions should ideally precede education. Patient activation level tended to decrease with age, suggesting that older patients may tend to a more

passive role in both self-management and decision making, a contributor to this may be framing of their illness as “old age”[4].

This work identifies a sub-set of patients who may benefit from enhanced activation, education and decision support in the low clearance setting. This will be the focus of a future intervention and outcomes from these patients will be reviewed.