

## Perceptions of Illness Severity, Treatment goals and Life Expectancy: The ePISTLE Study

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### Background:

In order to facilitate treatment matching individual beliefs, preferences and values, we need to accurately capture understanding of illness trajectories, expectations of care and perceived priorities of care-receivers and care-givers.

### Objectives:

To compare perceptions of prognosis, transplant candidacy, symptom burden and goals of care between seriously-ill haemodialysis patients, their close persons and healthcare providers (HCP).

### Methods:

Case-notes at three haemodialysis units were screened. A validated predictive mortality risk score<sup>1</sup> was calculated for patients: those with >20% 1-year mortality risk were included into the study. Patients, their close person(s), named nurse and lead doctor were all asked to take part in a structured interview or to complete a mixed-methods questionnaire. Completion of 2+ of these questionnaires formed a patient pack and was anonymised for entry into the study. Ethical approval was granted (18/LO/1386).

### Results:

334 patient notes were screened. 60 eligible patients were approached and 42 included into the study (14 declined, 3 questionnaires were not returned in the permitted time period and 1 patient pack was incomplete).

29/42 (69%) patients were male, median age was 76 years (inter-quartile range, IQR 65-83) and median length of time on dialysis was 39 months (IQR 19-56).

36% and 26% patients thought they would have >95% chance of being alive at 1 and 5 years. HCP predicted significantly lower survival (23.6% (95% CI 3.93) and 10.9 (95% CI 2.60 respectively), (P<0.0001 for both). Close persons were even more expectant of 1-year survival than patients (p<0.05). Only 2 of 15 patients expectant of 1-year survival (13%) preferred 'care focussing on relieving pain and discomfort' compared to 15/27 (56%) of those reporting a lower chance of survival.

Patients were significantly more likely to consider themselves transplant candidates than their nephrologists (p=0.02). Overall, 20/42 (48%) patients believed transplantation was an option for them, despite only 4 being wait-listed at the time of interview. Patients who thought they were on the transplant list were significantly more confident they would be alive at one year (98% vs 61%, p=0.002).

21 patients (50%) reported concerns about their memory and 10 (24%) patients had a formal diagnosis of cognitive impairment. Documented cognitive impairment or memory loss did not alter 1- or 5-year prognostic expectations (p=0.96, p=0.59) nor expectations of transplant candidacy (p=0.21).

Completion of the IPOS-Renal symptom score<sup>2</sup> highlighted a significant symptom burden amongst patients which was under-recognised by HCP (18.0 (SD1.8) vs 11.1 (SD1.0), (p=0.0005)). Close-persons' more accurately recognised patient's symptoms, with no significant difference between patient and close-person scores.

Most patients want to discuss their wishes regarding care towards the end of life (EoL). 10 patients recalled talking about their EoL care-plans with a HCP and 11/32 of those who did not, wanted this discussion to take place.

#### Conclusions:

There is a disparity between patient/close person estimations of prognosis and those of their nephrologists/nurses. Beliefs regarding prognosis and transplant candidacy affect treatment choices: patients who believe they will live longer preferred more radical care. Our findings suggest the need to improve communication about prognosis to both patients and their families.