

### 036 LIVING AND DYING WELL WITH ADVANCED KIDNEY DISEASE: THE FUTURE IS TOMORROW...?

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10.1136/bmjspcare-2012-000196.36

**Background** Patient identification and care planning are central to UK end-of-life policies. For patients on renal replacement therapy, dialysis withdrawal is the main cause of death. Most die in hospital after multiple admissions.

**Aims** An indepth, case study of a 24-bedded general renal ward explored the admission, assessment and discharge planning processes of patients identified after an unplanned admission as having unmet palliative care needs and a limited prognosis.

**Methods** The multi-disciplinary renal team worked with the researcher for two months to generate data from multiple perspectives. Patients were screened with a checklist of indicators for advanced disease. 58 (44%) were identified and followed for 3 months. A purposive sample of five patient – carer – GP triads were interviewed at home, soon after discharge. Patients completed a patient outcome score and staff a semistructured questionnaire. The researcher used the Workplace Culture Critical Analysis Tool for ward observations.

**Findings** Advanced kidney disease is punctuated by unplanned hospital admissions due to complications of treatment or comorbidities. Death often followed an acute deterioration that triggered dialysis withdrawal. Patients demonstrated fluctuating ambivalence about their illness and the future, using avoidance and disavowal to maintain hope. Professionals strived to balance patient wishes with ethical decisions about treatment. ‘Palliative care’ had negative connotations and advance ‘planning for dying’ was not a helpful construct.

**Conclusions** Patients receiving renal replacement therapy focus on short-term goals as they try to ‘live well’ with complex illnesses and treatment. Clinical indicators can be used to identify advanced kidney disease, but prognosis and likely mode of death are uncertain. Anticipatory care planning needs to engage patients and carers in ‘planning for uncertainty’ and could consider levels of intervention for the next acute episode. Making a planned transition to end-of-life care before the patient is dying can be complex and challenging.