

## NATIONAL SURVEY OF THE CURRENT PROVISION OF SPECIALIST PALLIATIVE CARE SERVICES FOR PATIENTS WITH END STAGE RENAL DISEASE (ESRD)

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**BACKGROUND:** The Department of Health (DoH) End of Life Care Strategy (2008) emphasizes the need for high quality end of life care (EOLC) regardless of age, diagnosis or care setting. The symptom burden of patients with ESRD is comparable to advanced cancer, but with notable evidence of under recognition and under treatment of symptoms in ESRD. The National Service Framework for Renal Services (DoH): Part 2 (2005) aims to improve EOLC for people with ESRD, with a key step being for renal networks to establish links with palliative care services, and, through use of end of life care tools, to support choice in treatment and place of death. Gunda et al (Nephrology, Dialysis & Transplant, 2004) undertook a survey of UK renal units to assess provision of palliative care services for renal patients and reported only 38% and 20% of renal units had usual or regular involvement of hospital palliative care teams and hospices, respectively. To meet the palliative and EOLC needs of ESRD patients better, an assessment of the current provision of specialist palliative care (SPC) services and the factors which enable or prevent access to these services is required. Knowledge of current SPC service provision will inform planning and coordination of future service development to meet the complex needs of ESRD patients.

**AIM:** To assess the current provision of specialist palliative care services for patients with ESRD in the hospital, hospice and community settings in the UK and to determine the factors that facilitate or prevent SPC provision to this group.

**METHOD:** An anonymous questionnaire was sent to the lead clinician for all hospital, hospice and community SPC organisations providing adult SPC services in the UK, identified from the Hospice and Palliative Care Directory 2008. A second mailing was sent to non-responding organisations after 35 days. The questionnaire was developed specifically for this study, drawing on questionnaires assessing the provision of SPC for patients with other non-malignant diseases. Data analysis was undertaken using SPSSv15, supported by the National Council for Palliative Care.

**RESULTS:** Questionnaires were sent to 610 SPC organisations. 317 were returned (response rate 52%). 33.6% had a renal unit on site. Most (88.6%) accepted referrals for patients with ESRD, but numbers of referrals per year are few: 88% of hospice inpatient services, 54% of hospital SPC teams and 77% of community SPC teams reported only 0-5 ESRD referrals per year, with only 2%, 14% and 3% respectively being referred >10 patients per year. 188/281 (67%) of respondents accepting ESRD patients stated that the major barrier to accepting more referrals was that "none or few were referred". 30 respondents (9.4%) did not accept patients with ESRD, of whom 20 reported that they only accept cancer patients. Only 23 respondents (7.3%) used specific referral criteria for ESRD. Specific treatment guidelines or pathways for patients with ESRD, other than EOLC tools, were used by 53 respondents (16.7%). 251 respondents (79.1%) used the Liverpool Care Pathway (LCP) or equivalent for patients with ESRD. Only 22 respondents (6.9%) took part in a joint multi-disciplinary team meeting of renal and palliative care professionals and 9 respondents (2.8%) held a joint outpatient clinic. 127/317 respondents commented on initiatives to improve palliative care for ESRD patients, with 33% of these identifying "closer working links and better communication with renal teams" and 39% "education of both SPC and renal teams" as beneficial. [nu1]

**CONCLUSIONS:** Most SPC services provide SPC to patients with ESRD. Currently, small numbers of ESRD patients access services, as few are referred. There is limited use of specific referral criteria and symptom control guidelines but a majority used the LCP for EOLC. Improving collaboration through education, joint MDT meetings and clinics, would enable delivery of SPC to increased numbers of ESRD patients, thereby improving their quality and experience of care.

