

NATIONAL SURVEY OF PALLIATIVE CARE IN END STAGE RENAL DISEASE IN THE UNITED KINGDOM

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PROBLEM: Palliative care for patients with end stage renal disease (ESRD) is a neglected aspect of nephrology. ESRD is more common in the elderly and many patients are deemed not suitable for dialysis treatment or become too frail to tolerate continued dialysis. There is very little evidence concerning palliative care provision in ESRD in the literature and there is anecdotal evidence of wide variation in practice in different renal units across the UK. The fourth module of the Renal National Service Framework, which will deal with conservative treatment of ESRD, will benefit from a better understanding of current practice. We carried out this survey to establish the current pattern of provision of palliative care for ESRD in the UK

DESIGN: An anonymous but numbered questionnaire concerning local palliative care provision was sent to clinical directors of all 69 UK renal units. The unit identities were known only to our administrator who did not see the responses and took no part in the analysis but was able to chase up outstanding responses and in this way a 100% response was obtained.

FINDINGS: Only 27 (39%) units employ staff with palliative care for ESRD patients as a specified part of their role. In 19 of these units staff spend less than four hours per week concerned with palliative care and only 5 units have staff work for more than twelve hours a week in this role. Fifty-five (80%) units do not have a written protocol for palliative care. Resources available for terminal renal patients were:

Questions	Never/ Rarely	Occasionally	Sometimes	Usually	Virtually always
Access to continuing care teams	9 (13)	23 (33)	11 (16)	15 (22)	11 (16)
Access to hospices	26(38)	19 (28)	10 (14)	12 (17)	2 (3)
Follow up in renal clinic	0	5 (7)	6 (9)	26 (38)	32 (46)

Anaemic ESRD patients with an expected survival of more than three months receive blood transfusion in 59 (86%) units, intravenous iron in 61(88%) units and erythropoietin in 63(91%) units. Only 37 (54%) of units kept a record of patients seen by the unit staff but deemed not suitable for dialysis.

CONCLUSION: There is a significant variation in provision and in some areas complete absence of palliative care services across the UK. In some areas access to palliative care is restricted to patients with malignant disease and ESRD patients are excluded.

RELEVANCE: Despite the widespread deficiencies in provision in the UK a few units manage to provide excellent standards of palliative care. This suggests it is not just a resource issue. Palliative care needs to be given a higher priority at local level, and existing services need to be made available to non cancer patients if we are to provide an adequate service for our patients.