

**Unmet palliative care needs among patients with end-stage kidney disease: a national registry study about the last week of life**

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**Background.** End-stage kidney disease (ESKD) is a condition with high mortality and complex end-of-life trajectories. However, access to specialized palliative care is limited. This underlines a need to explore care at end of life according to key components of palliative care.

**Aims.** To study symptom prevalence, symptom management and communication during the last week of life for patients with ESKD.

**Methods.** This registry study is based on data over two years from the Swedish Register of Palliative Care – a national quality register for end-of-life care irrespective of diagnosis and setting. Registry data was linked to the Swedish Causes of Death Certificate Register to identify patients (aged 18 or older) with chronic kidney disease (ICD-10; N18.5 or N18.9) reported as mortality reason and/or underlying cause of death.

**Results.** 472 patients reported as expected deaths were included. Pain was the most prevalent (69%) of six predefined symptoms, followed by rattles (46%) anxiety (41%), confusion (30%), shortness of breath (22%) and nausea (17%). Reported symptom relief was highest for pain and anxiety. Still 32% of patients with pain and 44% of patients with anxiety were only partly relieved or not relieved at all. A majority of patients (55%-84%) with the other symptoms were partly relieved or not relieved at all. The use of assessment scales was 14% for pain, and 9% for other symptoms. End-of-life discussions were reported for 41% of patients and for family members of 71% of patients. The patient's desire about place of death was reported as met in 41% and unknown in 56%. The majority (89%) of patients died in institutional care settings. Eight percent died in hospice care and 5% in palliative home care. Of all patients 19% died alone. Bereavement follow-up was offered to 38% of families. Altogether results show that there are remaining challenges for the provision of adequate palliative care for these patients which stresses the need for integrated palliative care.