

## JOURNAL CLUB

### **Symptoms in the Month Before Death for Stage 5 Chronic Kidney Disease Patients Managed Without Dialysis**

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Reference: JPSM 2010;40: 3, 342-352.

Murtagh, FE et. al. "Symptoms in the Month Before Death for Stage 5 Chronic Kidney Disease Patients Managed Without Dialysis." JPSM 2010;40: 3, 342-352.

#### Abstract:

There is little evidence on the symptoms experienced by those with advanced (stage 5) chronic kidney disease (CKD), managed without dialysis, as they approach death. As palliative care extends to noncancer illnesses, understanding symptom prevalence and severity close to death will clarify which symptom interventions are most needed and which elements of (largely cancer-driven) models of palliative care best translate into end-of-life care for this population.

**Objectives:** To determine symptom prevalence and severity in the last month of life for patients with Stage 5 CKD, managed without dialysis.

**Methods:** Longitudinal symptom survey in three UK renal units, using the patient-completed Memorial Symptom Assessment Scale-Short Form (MSAS-SF). We calculated the prevalence of individual symptoms (with 95% confidence intervals [CI] to reflect sample size), plus MSAS-SF subscales, in the month before death. Comparison is made with previously published data on symptoms in the last month of life in advanced cancer, also measured using the MSAS-SF.

**Results:** Seventy-four patients (mean age: 81 yrs; standard deviation [SD] : 6.8) were recruited (response rate: 73%); 49 (66%) died during follow-up (mean age: 81 yrs; SD: 5.7). "Month before death" symptom data were available for 43 (88%) of the 49 participants who died. Median time of data collection was 18 days from death (interquartile range: 12-26 days). More than half had lack of energy (86%; 95% CI: 73%-94%), itch (84%; 70-93%), drowsiness (82%; 68%-91%), dyspnea (80%; 66%-90%), poor concentration (76%; 61%-87%), pain (73%; 59%-85%), poor appetite (71%; 57-83%), swelling arms/legs (71%; 57%-83%), dry mouth 69%; 55-82%), constipation (65%; 50-78%), and nausea (59%; 44-73%). Levels of distress correspond to prevalence, with the exception of dyspnea, which was disproportionately more distressing. The median number of symptoms reported was 16.6 (range: 6-27), rising to 20.4 (range: 7-34) if additional renal symptoms were included. On average, psychological distress was moderate (mean MSAS-PSYCH: 1.55) but with wide variation (SD:0.50; range: 0.17-2.40), suggesting diverse levels of individual distress. The prevalence of both physical and psychological symptoms and the number reported were higher than those in advanced cancer patients in the month before death.

**Conclusion:** Stage 5 CKD patients have clinically important physical and psychological symptom burdens in the last month of life, similar or greater than those in advanced cancer patients. Symptoms must be addressed through routine symptom assessment, appropriate interventions, and with pertinent models of end-of-life care.

#### Strengths:

- Described prevalence of symptoms in a population (CKD pts who did not undergo dialysis) for whom it has not been well documented
- Well-validated tool (MSAS-SF) which is also used in studies involving symptoms cancer pts experience
- Comparison in clinical database between the study population and the population from which the sample was derived

#### Weaknesses:

- Relatively small study (n=43); pts unable to give consent were excluded but this decreases sample size further and also potential for bias (?more ill pts excluded)
- Relative/caregivers assisting pts in completing tools
- Tools very long compared to ESAS, no assessment of cognition of patients during the study (only assessed regarding capacity to consent at the beginning)
- Assessment of severity limited .. only few categories

#### Applicability to Palliative Care:

The experienced symptom burden for the patients in this study is significant and should not be over-looked. As palliative and end-of-life care evolves to more and more include the care of non-cancer patients, it is important to recognize the symptom issues in the non-cancer population as well as the distress they can cause.