

# **Palliative Care for Patients with Serious Illness: Symptoms, Goals, and Spiritual Care in the Last Six Months of Life**

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## **Abstract**

The National Academy of Medicine endorses palliative care for patients with serious illness to improve communication about goals of care, maximize quality of life, and increase patient-centered care. Palliative care can also reduce pain and symptom burden, intensity of treatment, and utilization of undesired medical intervention. From a public health perspective, palliative care can add value by simultaneously reducing healthcare costs and honoring patient values and preferences. However, the integration of palliative care into medical disease management is lacking due to the limited availability of specialty (i.e. board-certified) palliative care clinicians.

The lack of access to specialty palliative care clinicians poses a critical problem to patients with serious illness, particularly for those near the end of life. Primary palliative care is palliative care delivered by clinicians not trained in specialty palliative care: specialists in other fields (e.g., oncology, nephrology) and primary care clinicians who incorporate components of palliative care - such as symptom management, goals of care, and spiritual care - into their practices concurrently with disease management. Although clinical trials indicate primary palliative care can be effective, little research examines the integration of primary palliative care into practice or the effects of such care. The overarching goal of this dissertation is to conduct research that will inform the delivery of palliative care that is not reliant on the availability of specialty palliative care by assessing delivery of recommended elements of palliative care by specialty and non-specialty clinicians. This dissertation used data abstracted from the University of North Carolina (UNC) Medical Center electronic health record (EHR) to conduct three specific aims. Aim 1 develops an EHR phenotype to identify decedents with late-stage cancer (stage 4) and chronic kidney disease (CKD; Stages 4-5) to be applied in Aims 2 and 3 to build the analytic cohort, and which demonstrates the value of EHR phenotypes in research and clinical practice. Aim 2 identifies factors associated with three recommended elements of palliative care: pain and symptom management, goals of care, and spiritual care in the last six months of life. Likewise, Aim 3 examines the association of pain and symptom management, goals of care, and spiritual care with (1) in-hospital death and (2) hospice enrollment.

We found that elements of palliative care are being delivered for decedents with late-stage cancer, dementia, and CKD, but critical goals-of-care discussions, transitions to comfort care, and referral to hospice all happen very near death. Subsequent work will use findings from this dissertation to inform the design, implementation, and dissemination of primary palliative care interventions to provide recommended elements of palliative care to those who would otherwise not have access to specialty palliative care services.

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