Letters

Palliative Care Use and Patterns of End-of-Life Care in Hospitalized Patients With Calciphylaxis

Introduction

Calciphylaxis is a rare, debilitating condition characterized by extremely painful ischemic skin lesions and is associated with a one-year mortality of 25%–80% at the time of diagnosis.[1] End-stage renal disease (ESRD) patients with calciphylaxis have a worse prognosis than non-ESRD patients with the same condition.[1] In addition, nearly 50% of patients with calciphylaxis suffer from limited mobility due to severe pain, and more than 70% are hospitalized for severe skin ulcers.[1,2] Furthermore, calciphylaxis does not have any approved treatments although agents such as sodium thiosulfate have been reported to ameliorate skin lesions with varying efficacy.[1]

Despite the high rates of morbidity and mortality associated with calciphylaxis, and the lack of effective treatments, understanding of palliative care (PC) use and end-of-life (EOL) care in calciphylaxis patients is limited.[3] PC has been associated with improved EOL care in patients with incurable diseases—especially for patients with ESRD on dialysis who comprise the majority of calciphylaxis patients.[4] In this study, we sought to describe the frequency of PC consultations and patterns of EOL care among hospitalized patients with calciphylaxis before death.

Methods

We conducted this study using the centralized clinical data registry from the member hospitals and institutions of Partners HealthCare in Boston, Massachusetts. This retrospective data registry has been described in detail in previously published studies.[5]

We searched for the term "calciphylaxis" using the registry query tool among patients who died between January 1, 2014, and April 30, 2018. We then ascertained the diagnosis of calciphylaxis by performing chart reviews. Our criteria for a diagnosis of calciphylaxis were 1) a skin biopsy confirming the diagnosis based on pathology features and/or 2) a clinical diagnosis by a multidisciplinary calciphylaxis team (consisting of specialists from many disciplines including dermatology, plastic surgery, and nephrology). We applied the following inclusion criteria: 1) age 18 years or older at time of diagnosis and 2) patient had died as an inpatient as of April 30, 2018. Cause of hospitalization was not used to select patients.

This study was approved by the Institutional Review Board at Partners HealthCare, and the need for informed consent was waived.

Our outcomes of interest were 1) PC consultation, 2) receipt of cardiopulmonary resuscitation, (3) mechanical ventilation, (4) tube feeds, (5) vasopressor therapy, and (6) place of death during the patient's terminal admission. All variables were determined by chart review.

We ascertained demographic, comorbidity, and hospitalization data by chart review for all patients at the time of their terminal admission. Comorbidities listed at terminal admission were used to determine the Charlson Comorbidity Index.[6]

Results

Twenty-four patients met our eligibility criteria and were included in this analysis. The median age was 59 (interquartile range [IQR]: 53–70) years. The median time to death from terminal admission was 15 (IQR: 5–28) days. Fifty-four percent of patients were female and 79% were white. The median Charlson Comorbidity Index score was 6 (IQR: 4–7). Eighty-four percent of patients had ESRD requiring dialysis (70% on hemodialysis and 30% on peritoneal dialysis), and 8% had predialysis chronic kidney disease.

Fifty percent of all patients received an inpatient PC consult during their terminal admission (Table 1). Before death, 21% of patients received cardiopulmonary resuscitation and 46% were mechanically ventilated. Twenty-nine percent of patients

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Table 1
Palliative Care and Other Treatment Components During the Terminal Admission

Outcomes	Patients ($N = 24$)
Palliative care consultation (%)	50
Cardiopulmonary resuscitation (%)	21
Mechanical ventilation (%)	46
Tube feeds (%)	29
Vasopressor therapy (%)	42
Place of death	
Inpatient ward (%)	33
Intensive care unit (%)	54
Inpatient hospice (%)	13

received tube feeds, and 42% received vasopressor therapy. Thirty-three percent of patients died on an inpatient ward, 54% died in an intensive care unit, and 13% died in inpatient hospice. The median time to PC consultation from admission was 5 (IQR: 3–11) days. The median time to death following PC consultation was 17 (IQR: 7–38) days. Median duration of terminal admission was 20 (IQR: 8–29) days.

Discussion

In this retrospective study of hospitalized patients with calciphylaxis, we found that PC consultations occurred in only half of all patients and many patients received intense care during their terminal admission. These findings suggest the need to improve EOL care for calciphylaxis patients.

A recent systematic literature review of calciphylaxis publications investigated whether the role of PC, quality of life, and patient-reported outcomes were included in calciphylaxis studies.[3] The authors found that only eight of 233 articles reviewed mentioned the use of PC in the course of treatment.[3] This is consistent with our finding of low use of PC services in this population. The goal of PC is to relieve suffering and improve the quality of life for patients with advanced illnesses by management of symptoms as well as coordination of an array of supportive medical and social services.[7] Given the severe physical restrictions, pain, and life-threatening infections associated with calciphylaxis,[1,3] patients who are afflicted with this disease represent a population that would benefit greatly from PC involvement along the full disease spectrum—perhaps starting at the time of diagnosis. In addition, as hospitalization rates are exceedingly high among calciphylaxis patients,[1,2] inpatient PC consultation may offer more advance care planning, better symptom management, and improved quality of death for critically ill patients and their loved ones.[8] This is particularly relevant as the frequency of calciphylaxis is reportedly rising, a likely reflection of more awareness and/or increasing incidence of risk factors such as obesity.[1]

PC consultation has been associated with reduced intensity of EOL care in several patient populations and even improved survival in patients with cancer.[4] One retrospective study that investigated 57,573 decedents in the Veterans Affairs health system found that family-reported quality of EOL care was significantly better for patients with cancer and dementia compared with those with ESRD because of higher rates of PC consultation, do-not-resuscitate orders, and fewer deaths in the intensive care unit.[4] In addition, timing of PC consultations has been shown to affect patient outcomes. Wachterman et al. performed a study of 770,191 patients on maintenance hemodialysis and found that hospice referral within at least 15 days of death had the highest benefit in terms of lower health care utilization and costs of care.[9] In our study, the median time to death following PC consultation was 17 (7–38) days, which may reflect increasing awareness of the benefits of PC consultation. Nonetheless, our data build upon previous research that encourages timely inpatient PC consultations and hospice referrals for patients with ESRD given the increasing intensity of care at the EOL for this population.[10]

Our study has several limitations. The small sample size made it difficult to determine predictors of our variables of interest. We were also limited to studying inpatient care during the terminal admission, which did not permit for evaluating outpatient PC consultation or inpatient consultations on previous admissions. Furthermore, generalizability is limited as we analyzed data from teaching academic institutions in the greater Boston area. Despite these limitations, to our knowledge, this is the largest cohort study to evaluate PC use and EOL care patterns among patients with calciphylaxis.

In conclusion, hospitalized patients with calciphylaxis experience a low proportion of PC consultations and intense care at the EOL despite significant morbidity and mortality in this population. Our study highlights the need for improved integration of PC services into care for these patients to improve quality of EOL care.

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