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# End-of-Life Expenditure in the ICU and Perceived Quality of Dying

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**OBJECTIVE:** Although end-of-life care in the ICU accounts for a large proportion of health-care costs, few studies have examined the association between costs and satisfaction with care. The objective of this study was to investigate the association of ICU costs with family- and nurse-assessed quality of dying and family satisfaction.

**METHODS:** This was an observational study surveying families and nurses for patients who died in the ICU or within 30 h of transfer from the ICU. A total of 607 patients from two Seattle hospitals were included in the study. Survey data were linked with administrative records to obtain ICU and hospital costs. Regression analyses assessed the association between costs and outcomes assessing satisfaction with care: nurse- and family-assessed Quality of Death and Dying (QODD-1) and Family Satisfaction in the ICU (FS-ICU).

**RESULTS:** For family-reported outcomes, patient insurance status was an important modifier of results. For underinsured patients, higher daily ICU costs were significantly associated with higher FS-ICU and QODD-1 ($P < .01$ and $P = .01$, respectively); this association was absent for privately insured or Medicare patients ($P = .50$ and $P = .85$, QODD-1 and FS-ICU, respectively). However, higher nurse-assessed QODD-1 was significantly associated with lower average daily ICU cost and total hospital cost ($P < .01$ and $P = .05$, respectively).

**CONCLUSIONS:** Family-rated satisfaction with care and quality of dying varied depending on insurance status, with underinsured families rating satisfaction with care and quality of dying higher when average daily ICU costs were higher. However, patients with higher costs were assessed by nurses as having a poorer quality of dying. These findings highlight important differences between family and clinician perspectives and the important role of insurance status.

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**ABBREVIATIONS:** FS-ICU = Family Satisfaction in the ICU; LOS = length of stay; QODD-1 = Single-item quality of dying rating from the Quality of Dying and Death Questionnaire

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In the United States, 20% of patients die during a hospitalization with an ICU stay,[1] and 25% of our health-care costs are spent on the 6% of people who die each year.[2-4] Our aging population, coupled with medical advances, has led to an increasing number and proportion of ICU beds and increasing costs of critical care.[2,5,6] Whether these trends of increased ICU use are consistent with patient values and preferences or are associated with the quality of end-of-life care is unclear.

There is evidence to suggest that ensuring patient-centered care for those at high risk of death leads to a reduction in intensity of care near the end of life.[7-11] However, there is a notable discrepancy between the setting in which terminally ill patients prefer to die and the setting in which they actually die.[12,13] Teno and colleagues[14] found that ICU use in the last 30 days of life increased between 2000 and 2009 despite public opinion surveys reporting that most patients would prefer to die at home if diagnosed with a terminal illness.[13] In a study of patients with advanced cancer recruited from the outpatient setting, higher medical costs in the final week of life were associated with more physical distress and worse overall quality of death as perceived by the family caregiver.[15] For patients who die in the ICU, the association between hospital costs at the end of life and quality of death remains unclear.

The objectives of our study were to investigate the associations between ICU or hospital costs at the end of life and family- or nurse-reported outcomes for patients who died in, or shortly after a stay in, the ICU. For families, these outcomes include ratings of the quality of dying and satisfaction with care in the ICU; for nurses, outcomes include ratings of the quality of dying. We hypothesized that higher costs at the end of life, reflecting longer length of ICU stays and more invasive, aggressive treatment, could have a negative impact on the quality of dying and satisfaction with care for family members of patients who die in the ICU. We also hypothesized that the impact of an expensive ICU stay on quality of dying and satisfaction with care would be most pronounced in the uninsured/underinsured and other patients of lower socioeconomic status.

## Materials and Methods

### *Design Overview*

Data were collected as part of two studies (a before-after trial and a cluster-randomized trial) of an interdisciplinary, multifaceted intervention to improve the quality of end-of-life care for critically ill patients and their families.[16-18] Eligible patients were those who had died in an ICU after a minimum stay of 6 h or within 30 h of transfer from the ICU to another hospital location. Questionnaires were sent to patients' homes 4 to 6 weeks after death, addressed to "the family of" the patient, requesting a response from the person most knowledgeable about the patient's end-of-life experience. Nurse questionnaires were distributed within 72 h of death to the hospital mailbox of the nurse caring for the patient at the time of death/transfer and the nurse from the prior shift. Data were linked to hospital financial records to obtain detailed cost information on hospital and ICU expenditures. All procedures were approved by the institutional review boards at all institutions (UW HSC#23503).

### *Setting*

The two hospitals in this study are both part of a single network and, therefore, had a common system for calculating ICU and hospital costs. The hospitals included one academic level I trauma center and one community-based hospital.

### *Outcome Measures*

Outcome measures were the nurse- and family-assessed Quality of Death and Dying (QODD-1) rating and the Family Satisfaction in the ICU (FS-ICU) questionnaire's total score. The QODD-1 provides a succinct measure of the overall quality of dying using a single-item summary question: "Overall, how would you rate the quality of your loved one's dying?" Ratings range from zero (a "terrible" experience) to 10 (an "almost perfect" experience). The QODD-1 has been associated with the quality of ICU palliative care.[19]

The FS-ICU is a reliable and valid 34-item tool designed to measure family satisfaction with ICU care.[20,21] Recently, the FS-ICU was reduced to 24 items, and a validated scoring method was developed.[22] Higher values indicate increased satisfaction. The survey is available online.[23]

### *Cost Variables*

Total hospital and total ICU costs, rather than charges, were obtained from administrative financial databases. Charges bear little resemblance to costs, and use of charges as a proxy for costs may lead to unwarranted conclusions about economic efficiency.[24] Therefore, we chose to use actual costs. The reported costs represent indirect and direct costs and include all facility and professional fees, with the exception of physician fees. Collectively, these costs represent the total costs for all services provided on each hospital day, including overhead costs, labor costs, and supply costs. Direct costs represent costs that are traceable back to a specific cost center providing direct patient care, such as pharmacy, radiology, respiratory, microbiology, and hematology. Indirect costs, which are included in the patient bill, represent services provided by cost centers not directly linked to patient care, such as information technology, environmental services, and hospital administration. In this network of hospitals, physician fees are not generated in a similar way at each institution and were, therefore, not included. To obtain average daily costs, total ICU costs were divided by the ICU length of stay (LOS). All costs were adjusted for inflation and compared at the 2013 US dollar value. Because of the skewness of the cost data, we use the log-transformed value.

### *Covariates*

We determined patient age, sex, and insurance type from the medical record. Insurance type was assessed in four categories (private insurance, Medicare, Medicaid, no insurance). For the purposes of these analyses, we assess insurance as insured (private insurance, Medicare) and underinsured (Medicaid, no insurance) based on a prior validation of this approach.[25] For associations found to be significant, we conducted sensitivity analyses in which we examined results of regression models across the four uncollapsed insurance categories. Patient race, education, and underlying cause of death were determined from the death certificate. In addition, we used median household income by zip code using the patient's zip code listed on the death certificate and census tract data.[25] We determined family member's age, sex, level of education, spouse vs other relationship, and presence at the time of death from family surveys and nurses' age and sex from nurse surveys.