

# Differences in Code Status and End-of-Life Decision Making in Patients With Limited English Proficiency in the Intensive Care Unit

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## Abstract

**Objective:** To determine whether code status, advance directives, and decisions to limit life support were different for patients with limited English proficiency (LEP) in the intensive care unit (ICU) as compared with patients whose primary language was English.

**Patients and Methods:** We conducted a retrospective cohort study in adult patients admitted to 7 ICUs in a single tertiary academic medical center from May 31, 2011, through June 1, 2014.

**Results:** Of the 27,523 patients admitted to the ICU, 779 (2.8%) had LEP. When adjusted for severity of illness, sex, education level, and insurance status, patients with LEP were less likely to change their code status from full code to do not resuscitate during ICU admission (odds ratio [OR], 0.62; 95% CI, 0.46-0.82;  $P < .001$ ) and took 3.8 days (95% CI, 1.9-5.6 days;  $P < .001$ ) longer to change to do not resuscitate. Patients with LEP who died in the ICU were less likely to receive a comfort measures order set (OR, 0.38; 95% CI, 0.16-0.91;  $P = .03$ ) and took 19.1 days (95% CI, 13.2-25.1 days;  $P < .001$ ) longer to transition to comfort measures only. Patients with LEP were less likely to have an advance directive (OR, 0.23; 95% CI, 0.18-0.29;  $P < .001$ ), more likely to receive mechanical ventilation (OR, 1.26; 95% CI, 1.07-1.48;  $P = .005$ ), and more likely to have restraints used (OR, 1.36; 95% CI, 1.11-1.65;  $P = .003$ ). The hospital length of stay was 2.7 days longer for patients with LEP. Additional adjustment for religion, race, and age yielded similar results.

**Conclusion:** There are important differences in end-of-life care and decision making for patients with LEP.

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Approximately 1 of every 12 adults in the United States has limited English proficiency (LEP) according to 2013 United States Census Bureau estimates.<sup>1</sup> Between 1990 and 2013, the adult population with LEP grew from 6.1% (14.0 million) to 8.5% (25.1 million). Although most of the population with LEP in the United States speaks Spanish (64%), up to 350 languages are spoken.<sup>1</sup> *Limited English proficiency* is defined as “not speaking English as a primary language and potentially having a limited ability to read, speak, write or understand English.”<sup>2</sup> Language barriers are associated with numerous adverse health outcomes such as longer hospital stays,<sup>3</sup> increased rates of hospital readmission,<sup>4</sup> lower rates of understanding discharge instructions,<sup>5</sup> lower satisfaction,<sup>6-8</sup> lower rates of receiving

recommended preventive medical services,<sup>9,10</sup> decreased rates of medication adherence,<sup>11</sup> deferring needed medical care,<sup>12</sup> lower rates of having a primary care provider,<sup>13</sup> compromised patient-physician communication,<sup>14</sup> and higher health care utilization and cost.<sup>15</sup>

Because communication is an essential component of decision making at the end of life, patients with LEP are at specific risk for suboptimal decision making. In the outpatient setting, patients with language barriers are at risk for lower quality of end-of-life care, suboptimal discussions about goals of care, not having an accurate understanding of their diagnoses and prognoses, and receiving suboptimal symptom control.<sup>16-18</sup> Family members of patients with LEP in the intensive care unit (ICU) are at risk for receiving less



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information and less emotional support during ICU family conferences.<sup>19</sup> Knowledge gaps exist regarding the effect of LEP on decision making for life support and at the end of life for hospitalized patients in the ICU. Understanding such knowledge gaps is critical to identifying methods to improve communication and decision making.<sup>20</sup> The objective of this study was to determine whether code status, advance directives, life support preferences, use of comfort measures before death, and timing of decision making were different for patients with LEP in the ICU as compared with patients who spoke English.

## PATIENTS AND METHODS

### Setting and Study Design

We conducted a retrospective cohort study in all adult patients admitted to 7 ICUs (medical, neurologic, cardiac, mixed, and 3 surgical) in a single tertiary academic medical center from May 31, 2011, through June 1, 2014. The Mayo Clinic Institutional Review Board approved the study protocol. The inclusion criteria were patients 18 years or older who were admitted to the ICU and gave research authorization. There was no contact with patients.

### Limited English Proficiency Definition

*Limited English proficiency* was defined as a primary language other than English.<sup>2</sup> For this study, LEP was measured as a primary language other than English in the electronic medical record, consistent with the definition used in several previous publications.<sup>21-23</sup> This variable was abstracted from the electronic medical record using an automated retrieval query. The accuracy of the automated retrieval query was verified by manual abstraction of a sample of 100 records. Limited English proficiency status for patients whose primary language or interpreter use was unknown was verified by manual chart abstraction.

### Data Collection

The following demographic variables were abstracted for each patient from registration data in the electronic medical record: age, sex, race and ethnicity, marital status, religion, education level, and insurance status. Medical

complexity was assessed by the Charlson Comorbidity Index, which considers the number and severity of 19 predefined comorbid conditions (as identified by *International Classification of Diseases, Ninth Revision* codes) and provides a weighted score of a patient's comorbidities.<sup>24</sup> The Acute Physiology and Chronic Health Evaluation (APACHE) III score was calculated for each patient to assess illness severity on admission to the ICU and 24 hours after admission.<sup>25</sup>

The primary outcomes of the study were characteristics of decision making for life support, code status, and aggressiveness of treatment<sup>26</sup> and included code status on ICU admission, code status on ICU discharge, change in code status during ICU stay, use of life support (invasive mechanical ventilation, noninvasive mechanical ventilation, dialysis, vasopressors, and cardiopulmonary resuscitation), presence of advance directives, and implementation of a standardized institutional comfort measures only order set. Secondary outcomes included use of restraints, documentation of a family conference, the presence of symptoms<sup>26</sup> (delirium, pain, and agitation), ICU and hospital length of stay and mortality, and hospital discharge location. All outcomes were collected from the electronic medical record using automated retrieval queries. For patients for whom the presence of advance directives was not available using an automated search query, manual chart abstraction and imputation strategies were used.

Presence of pain was defined as either a pain score of 3 or greater on a 0 to 10 numeric pain intensity scale or a Face, Legs, Activity, Cry, and Consolability scale score of 5 or greater in the final 24 hours of the ICU stay.<sup>27</sup> Agitation was defined as a Richmond Agitation-Sedation Scale score of 2 or greater in the final 24 hours of the ICU stay.<sup>28</sup> Confusion was indicated by a positive scoring on the Confusion Assessment Method for the ICU (CAM ICU) in the final 24 hours of the ICU stay.<sup>29</sup>

### Statistical Analyses

All continuous variables were reported as medians with interquartile ranges. To minimize the effects of outliers and variables with non-normal distributions, Wilcoxon rank-sum tests were used to compare continuous variables between groups. We performed multivariate

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