

Factors associated with costly and potentially burdensome hospital care among patients with  
dementia and respiratory failure

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**Abstract**

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Understanding contributors to costly and potentially burdensome hospital care for critically ill patients with dementia is of interest to healthcare systems and may facilitate efforts to ensure care is concordant with patients' goals. We conducted an electronic health record (EHR)-based retrospective cohort study of 298 adults with dementia identified using International Classification of Diseases codes. Patients were hospitalized with respiratory failure (receiving  $\geq$

2 days mechanical ventilation) at one of two teaching hospitals in Seattle, Washington between 2011 and 2017. We collected patient demographic and clinical characteristics from the EHR, including clinical markers of advanced dementia (weight loss, pressure ulcers, hypernatremia, or mobility limitations) and clinical service (medical, surgical, neurologic). We measured multimorbidity using the Deyo-Charlson Comorbidity Index. We ascertained whether a goals-of-care discussion (GOCD) was documented in the EHR within 48 hours of intensive care unit (ICU) admission using a validated natural language processing algorithm. Logistic regression was used to identify characteristics associated with high hospitalization costs measured using the hospital system's accounting database and defined as total cost in the top third of the sample ( $\geq \$145,000$ ). We found that only a minority of patients (31%) had a GOCD documented within 48 hours of ICU admission. Adjusting for other measured characteristics, patients for whom a GOCD was documented within 48 hours of ICU admission had a 50% lower risk of a high-cost hospitalization (RR 0.50, 95% CI 0.2-0.9). Older age, limited English proficiency, and residing in a nursing home were also associated with lower likelihood of high-cost hospitalization, whereas greater comorbidity burden and admission to a surgical or neurologic ICU as compared to a medical ICU were associated with a higher likelihood of high-cost hospitalization. In conclusion, in this cohort study having an early GOCD in the ICU for patients with dementia and respiratory failure was associated with lower total hospitalization costs. However, understanding the nature of the association, causal or non-causal, likely will require the conduct of a randomized trial.

## **INTRODUCTION:**

Alzheimer's disease and related dementias (ADRD) are progressive, incurable, and represent leading causes of morbidity and mortality among a rapidly growing population of older adults in the United States.<sup>1</sup> Current national health care costs for people living with dementia in the United States are substantial and expected to rise in parallel with these epidemiologic trends. Estimates from 2010 demonstrated total healthcare costs attributable to dementia to be between \$157 and \$215 billion dollars annually, with Medicare paying approximately \$11 billion of this cost, and also with a financial burden placed on patients and their families.<sup>2</sup> In addition, a prior systematic review of costs of dementia care demonstrated that they increase considerably in the last 12 months of life, rising from a monthly total of \$1,787-2,999 USD per patient to \$4,570-11,921 USD in the last month before death.<sup>3</sup> This trend is thought to reflect an increase in hospital admissions and emergency department visits. There is broad interest among hospital systems, healthcare providers, and health policy experts in improving the value of care delivered to patients with dementia in particular at more advanced stages and end-of-life.

Respiratory failure is the most common reason for hospitalization among people with dementia.<sup>4,5</sup> Recently, concerns have been raised regarding a trend towards increasing use of mechanical ventilation (MV) among people living with advanced dementia who develop respiratory failure, without an associated improvement in survival.<sup>6-9</sup> Prior studies have also demonstrated that most (over 90%) people with advanced dementia and their family members prefer comfort- over longevity-focused care.<sup>4,10,11</sup> MV, which is both invasive and costly, is of low value to patients who prioritize comfort as their primary healthcare goal, and concerns have been raised that the trends of increasing MV use over time are not driven by patient and family preferences.<sup>6</sup> Among adults with severe chronic illness requiring MV for acute respiratory

failure, a diagnosis of dementia has been reported to be associated with higher hospitalization costs, suggesting a need for greater investment in communication strategies and supportive care programs to ensure that this care is consistent with patients' goals.<sup>12</sup> A better understanding of the drivers of high-cost, high-intensity care for patients with dementia is necessary in order to identify opportunities to promote patient-centered, goal-concordant care. The aims of this study were to identify clinical and demographic factors among people living with dementia hospitalized for acute respiratory failure associated with high hospitalization costs, and specifically to test the hypothesis that an early discussion of the goals of care between providers of care and family members is associated with lower hospitalization costs.

## **METHODS:**

### **Study Design and Cohort**

This was a retrospective cohort study. The UW Medicine electronic health record (EHR) and financial records served as the primary data sources, with variables collected through a combination of automated abstraction of discrete data elements by an experienced data specialist and manual chart review by the first author (L.P.). The study cohort consisted of adults age 40 and older living with dementia who were admitted to an intensive care unit (ICU) for respiratory failure requiring MV support continuously for at least two days at one of two teaching hospitals (a county and tertiary care hospital) within UW Medicine between January 1, 2011 and December 31, 2017. Patients were identified as having ADRD if they had an International Classification of Diseases (ICD) -9 or -10 code indicating a diagnosis of dementia entered prior to the index hospitalization admission date. Use of ICD-9 and -10 codes to identify patients with dementia has been previously validated against clinical reference standards.<sup>13-15</sup> For patients with

multiple eligible hospital admissions, we included data from the first admission within the designated time period. Data on treatment with MV and the number of hours treated were automatically abstracted from a nurse-charted structured field in the EHR. This method for ascertaining treatment with MV has been previously validated within the UW Medicine EHR by manual chart review.<sup>16</sup>

### **Outcome Variable**

The outcome chosen for this study was high-cost hospitalization, defined dichotomously as whether the total cost of the index hospitalization was within the top third of the overall sample. Total hospitalization costs included both direct and indirect costs associated with hospital care and professional services. Direct costs are those that vary at the individual level (medications, procedures, tests, consumable equipment, and proportionate staffing costs) whereas indirect costs cannot be attributed to an individual patient but are global costs shared proportionately across patients. Costs were abstracted from the UW Medicine accounting database, adjusted for inflation to represent the value as of June 1, 2019. This method for ascertaining hospitalization costs reflects the best available quantification of resources attributable to the care of a specific patient.<sup>12,17</sup>

### **Exposures, mediators, and descriptive variables**

Using EHR data from each index hospitalization, data abstraction was performed to ascertain participant clinical and demographic factors present at time of admission and characteristics of the hospitalization. All variables were automatically abstracted from the EHR with the exception of nursing home residence, which was manually abstracted from review of social work documentation. We ascertained patient demographic and clinical characteristics including age, sex, patient- or proxy-reported race and ethnicity, whether the patient had limited

English proficiency (derived from the recorded preferred language for medical care), comorbidities (computing the Deyo-Charlson comorbidity index score<sup>18</sup>), zip code (computing the state-normed Area Deprivation Index<sup>19</sup> as a measure of neighborhood socioeconomic disadvantage), type of health insurance (private, Medicare, Medicaid, military, other type, uninsured), and the number of Emergency Department (ED) visits or hospitalizations in the year prior to the index hospitalization admission date. We categorized participants as under-insured if they had Medicaid or no insurance. We defined high healthcare utilization in the year prior to admission as having had two or more ED visits or hospitalizations. We assessed the presence of four clinical markers of advanced dementia, including (1) dehydration, ascertained as a sodium level greater than 145 mmol/L on admission or a pre-admission ICD-9 or -10 code for hyponatremia, (2) weight loss of greater than 10lb over one year preceding admission or a pre-admission ICD-9 or -10 code for weight loss, (3) a pre-admission ICD-9 or -10 code for pressure ulcers, and (4) a pre-admission ICD-9 or -10 code for limited mobility. These markers were chosen because they are consistently reported in the EHR, have been shown to be associated with advanced dementia, and have been utilized in prior studies.<sup>20-23</sup> We abstracted characteristics of the hospitalization including the type of ICU the patient was admitted to (medical, surgical, or neurologic), the duration of MV use (days), the ICU and hospital lengths of stay (days), whether a goals of care discussion was documented in the EHR within 48 hours of ICU admission, and whether the patient died during the index hospital admission.

## **Statistical Methods**

Categorical variables were described in frequencies and percentages. Measures of central tendency and variability were reported for continuous variables. Exposure variables hypothesized to be associated with high hospital cost were selected *a priori*, and included (1)

age, (2) limited English proficiency, (3) being under-insured, (4) living in a nursing home, (5) high healthcare utilization in the year prior to admission, (6) ICU type, (7) the Deyo-Charlson comorbidity index score, and (8) whether a goals of care discussion was documented in the EHR within 48 hours of ICU admission. To assess associations between exposure variables and the outcome, we performed multivariable logistic regression with robust standard errors in which all eight predictors were included. Given the high prevalence of the outcome in this cohort (defined *a priori* as the upper third of hospitalization costs for the sample), we converted adjusted odds ratios to adjusted risk ratios using established methods.<sup>24</sup> All analyses were performed using STATA, version 16.0 (StataCorp., College Station, TX) statistical software.

## **RESULTS:**

### **Patient Characteristics**

A total of 298 patients with AD RD who were treated with MV for greater than two days were included in the study, and the 100 patients with total hospitalization cost in the highest third of the sample were categorized as the “high-cost” group. This high-cost group included patients whose total cost for the index hospitalization was at least \$145,000. Descriptive characteristics of the entire study sample as well as the proportion of patients with each exposure among those with high versus lower total hospitalization costs are displayed in Table 1. The median age among patients in the high-cost group was 64 as compared to 73 in the lower-cost group. There were fewer patients in the high-cost group as compared to the lower-cost group with limited English proficiency (9% vs 26%) and who were residing in a nursing home prior to hospitalization (7% vs 26%). The proportion of patients who were under-insured and the proportion who had high healthcare utilization were similar across the high- and lower-cost

groups (44% versus 51% and 31% versus 26% respectively). The median Deyo-Charlson comorbidity index was 4 in both the high- and lower-cost groups indicating a similar comorbidity burden. About half of the patients (49%) were admitted to a medical ICU, about a third (29%) to a surgical ICU, and 22% were admitted to a neurologic ICU. There were more patients in the high-cost group as compared to the lower-cost group who were admitted to a surgical or neurologic ICU (42% versus 23% and 28% versus 19% respectively). Only about a third (31%) of patients in the overall sample had a goals of care discussion documented within 48 hours of ICU admission. Those with a goals of care discussion documented within 48 hours of admission made up a lower proportion (15%) of the high-cost as compared to the lower-cost group (39%).

### **Factors Associated with High-Cost Hospitalization**

Patients who were older (RR 0.96 per one-year unit increase, 95% CI 0.94-0.98), had limited English proficiency (RR 0.53, 95% CI 0.26 – 0.99), or who resided in a nursing home (RR 0.36, 95% CI 0.16 – 0.76) had lower likelihood of a high-cost hospitalization (Figure 1). Patients with a greater comorbidity burden (RR 1.09 per each one-unit increase in Deyo-Charlson comorbidity index score, 95% CI 1.01-1.17) and those who were admitted to a surgical or neurologic ICU as opposed to a medical ICU (RR 2.00, 95% CI 1.35-2.50 and OR 2.11, 95% CI 1.48-2.62 respectively) were more likely to have a high-cost hospitalization. Patients for whom there was documentation of a goals of care discussion within 48 hours of ICU admission were less likely to have a high-cost hospitalization (RR 0.50, 95% CI 0.28-0.85). Being under-insured, having at least one clinical marker of advanced dementia, and high healthcare utilization in the year prior to admission were not associated with hospitalization cost.

### **DISCUSSION:**

In this study, we found that early documentation of a goals of care discussion, within 48 hours of ICU admission, was associated with a lower likelihood of high-cost hospitalization for patients with ADRD hospitalized for respiratory failure and treated with MV. This finding adds to the existing literature on palliative care delivery for acutely ill patients with ADRD by identifying a potential opportunity to provide high-value care by ensuring that aggressive life support interventions are aligned with patients' values and preferences *early* in the critical illness trajectory. We also identified patient clinical and demographic factors associated with high-cost hospitalization; patients who were older, had limited English proficiency, or who resided in a nursing home were less likely to have a high-cost hospitalization, whereas those with greater comorbidity burden and those who were admitted to a surgical or neurologic ICU as opposed to a medical ICU were more likely to incur high costs.

In cases where initial treatment with MV is aligned with patient goals, or there is uncertainty, communication with surrogate decision-makers in the ICU after intubation is the primary mechanism for delivery of goal-concordant care throughout the illness trajectory.<sup>25</sup> Goals of care discussions between healthcare providers and patients with life-limiting illness or their proxy decision-makers have been shown to be associated with subsequent less aggressive care choices.<sup>26-28</sup> However, few rigorously-designed studies have assessed the optimal timing of such discussions in ICU settings. Ideally, conversations about treatment goals and end-of-life care planning should begin in the outpatient setting, prior to development of critical illness and with a trusted healthcare provider,<sup>29</sup> but numerous barriers hinder these discussions and there have been recent calls for a shift in focus towards real-time discussions at the time that treatment decisions must be made over advance care planning.<sup>30,31</sup> The need for updated models of care that promote serious illness communication across healthcare settings for patients with ADRD in

particular is further supported by studies demonstrating that medical care towards the end-of-life for people with ADRD is more intensive compared to those without ADRD, and that surrogate decision-makers are frequently dissatisfied with this care.<sup>27</sup> In our study, we found that a minority (only 31%) of patients with ADRD treated with MV for respiratory failure had a goals of care discussion documented within 48 hours of ICU admission. Given the strong association we identified between early goals of care discussion documentation and hospitalization cost, future work might further investigate the impact of early goals of care discussion in the ICU on patient and family-centered outcomes such as satisfaction with care and psychological distress. This could lend support for future interventional trials focused on providing high-value care in the ICU for patients with ADRD and their families through upfront communication and palliative care delivery.

Our finding that patients with ADRD admitted to a surgical or medical ICU were more likely to have a high-cost hospitalization compared to those admitted to a medical ICU also has several potential implications. This finding aligns with the existing literature examining communication and palliative care delivery for patients in surgical ICU settings. Prior work has demonstrated that palliative care delivery metrics vary by ICU type, thought to reflect differences in ICU culture, policies, processes of care, attitudes, and patient clinical characteristics.<sup>32,33</sup> While many older adults admitted to surgical ICUs do not undergo surgery (for example, patients in need of monitoring after traumatic injury), a diagnosis of ADRD has been shown to be a risk factor for early post-operative mortality and higher likelihood of new admission to a long-term care facility.<sup>34,35</sup> Kalbfell et. al. have shown that pre-operative discussions with older adults undergoing major surgery infrequently explored patients' preferences for post-operative life-sustaining treatments.<sup>36</sup> To our knowledge, no prior studies

have described the frequency of goals of care discussions in surgical ICU settings. Our findings suggest that development of interventions targeting patients with ADRD admitted to surgical ICUs are needed.

Advance identification of patients with ADRD and acute respiratory failure at highest risk of receiving high-intensity and costly care has the potential to aid healthcare providers in prioritizing communication and palliative care interventions for those most likely to benefit from them. We found that patients with a greater comorbidity burden were more likely to incur high hospitalization costs, suggesting that patients with ADRD in addition to other serious chronic health conditions may be particularly likely to benefit from high-quality, early serious illness communication. The increasing prevalence of multimorbidity among older adults admitted to ICUs in the United States underscores the significance of understanding its impact on treatment decision-making in this setting.<sup>37</sup> Patients who were older and those residing in a nursing home were more likely to have a goals of care discussion documented within 48 hours of ICU admission, spent fewer days in the hospital, and were less likely to have high hospitalization costs. This likely reflects in part greater in-hospital mortality, but given the relationships between each exposure and early documented goals of care discussion, it may also reflect greater interest on the part of healthcare providers and patients' surrogate decision makers in having these conversations early.

This study has limitations that are important to note. There was no randomization, thus unmeasured patient characteristics predictive of a poor prognosis and a high likelihood of death could confound the results. Furthermore, we could not isolate the impact of an early GOCD on costs of hospitalization from factors associated with it: (1) physicians may be more likely to initiate an early GOCD for the sickest patients, who are also more likely to die earlier during

hospitalization, resulting in lower costs; and (2) physicians who initiate an early goals of care discussion may also be more likely to align treatment decisions with patient preferences through additional mechanisms, resulting in lower costs. While we included data from two hospitals, the study was limited to a single region and healthcare system which limits the generalizability of results. We relied on diagnosis codes used for billing purposes to identify patients living with ADRD; however, diagnosis codes have been shown to have high sensitivity and specificity for clinical ADRD,<sup>14,38,39</sup> and this strategy has been utilized in prior studies of trends in MV use allowing for comparability of results.<sup>40,41</sup> EHR data do not routinely capture patients' cognitive performance or functional status, and many patients living with ADRD do not undergo regular cognitive evaluations. To address this, we utilized surrogate clinical markers of advanced dementia. These measures are imperfect, but are consistently reported in the EHR, have been shown to be associated with advanced dementia, and have been used in prior studies.<sup>20-23</sup> Future prospective studies might incorporate informant-based cognitive assessments, such as the Dementia Severity Rating Scale.<sup>42</sup> Finally, we relied on EHR documentation of a goals-of-care discussion to ascertain whether such a discussion took place; this strategy would not have captured goals-of-care discussions that were not documented. In addition, we were also unable to assess the quality of these discussions.

In conclusion, the findings from this study support that the hypothesis that initiating goals-of-care discussions early for patients with dementia and respiratory failure may be a mechanism by which healthcare providers can achieve dual goals of aligning treatments with patients' preferences and effectively allocating healthcare resources. Nonetheless, because of the limitations inherent in research of this sort, at present no firm conclusions can be drawn.

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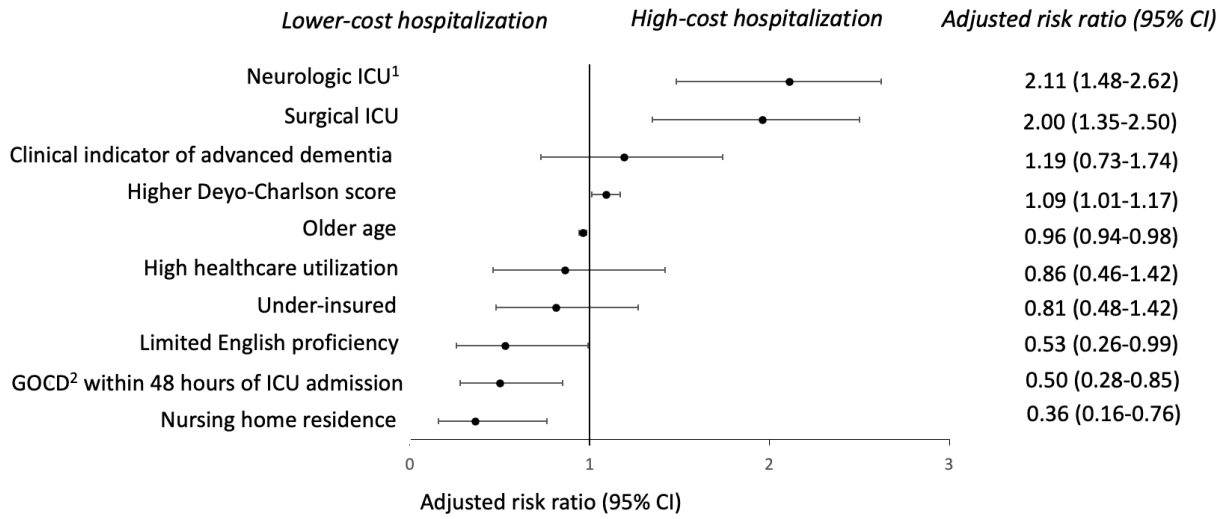
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**Table 1. Total hospitalization costs in relation to characteristics of 298 patients with dementia treated with at least 48 hours of continuous mechanical ventilation**

	Lower-cost <sup>a</sup> (n=198)	High-cost <sup>b</sup> (n=100)	Total (n=298)
Age at admission (years), median (IQR)	73 (18)	64 (17)	71 (17)
Race, n (%)			
White	118 (60)	68 (68)	186 (62)
Black	26 (13)	18 (18)	44 (15)
Asian or Pacific Islander	38 (19)	8 (8)	46 (15)
Indigenous	6 (3)	3 (3)	9 (3)
Other or unknown	10 (5)	3 (3)	13 (4)
Hispanic ethnicity, n (%)	3 (2)	1 (1)	4 (1)
Limited English proficiency <sup>c</sup> , n (%)	51 (26)	9 (9)	60 (20)
Deyo-Charlson Index Score, median (IQR)	4 (4)	4 (5)	4 (4)
Admitted from nursing home, n (%)	51 (26)	7 (7)	58 (20)
Under-insured <sup>d</sup> , n (%)	100 (51)	44 (44)	144 (48)
High healthcare utilization <sup>e</sup> (%)	52 (26)	31 (31)	83 (28)
Clinical indicator of advanced dementia, n (%)	118 (60)	57 (57)	175 (59)
Hypernatremia	65 (33)	21 (21)	86 (29)
Weight loss	76 (38)	44 (44)	120 (40)
Pressure ulcers	24 (12)	7 (7)	31 (10)
Mobility limitation(s)	29 (15)	10 (10)	39 (13)
ICU <sup>f</sup> type, n (%)			
Medical ICU	115 (58)	30 (30)	145 (49)
Surgical ICU	45 (23)	42 (42)	87 (29)
Neurologic ICU	38 (19)	28 (28)	66 (22)
Goals of care discussion documented within 48 hours of ICU admission (%)	78 (39)	15 (15)	93 (31)
Days in hospital, median (IQR)	12 (11)	39 (34)	18 (21)
Days in ICU, median (IQR)	8 (7)	21 (15)	10 (12)
Days treated with MV, median (IQR)	5 (4)	11 (13)	6 (7)
Died during index hospitalization, n (%)	72 (36)	12 (12)	84 (28)

<sup>a</sup>Total hospitalization cost in bottom two-thirds of sample; <sup>b</sup>Total hospitalization cost in upper one-third of sample; <sup>c</sup>derived from the recorded preferred language for medical care; <sup>d</sup>patient had Medicaid or no insurance; <sup>e</sup>two or more emergency department visits or hospitalizations in the year prior to the index hospitalization; <sup>f</sup>intensive care unit; <sup>g</sup>mechanical ventilation

**Figure 1.** Factors associated with high-cost hospitalization (total hospitalization cost in highest one-third of sample;  $\geq$  \$145,000) compared to lower-cost hospitalization (total hospitalization cost in bottom two-thirds of sample;  $<$  \$145,000) among 298 patients with dementia hospitalized for respiratory failure



<sup>1</sup> Intensive care unit

<sup>2</sup> Goals of care discussion