**Variations in Treatment Intensity at End of Life:
Review of Evidence and Policy and Program Implications**

by

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**ABSTRACT**

Gerald Mark Barron, MPH

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Robert Ferguson, MPH

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**Background:** U.S. regions with higher intensity of end-of-life (EOL) care do not have greater patient demand for such treatment, nor do they have better outcomes, mortality, quality of care, or satisfaction. This inefficiency has significant public health importance, because resources for improving the public’s health are limited and must be used wisely. This review categorizes factors associated with variations in EOL treatment intensity and proposes targeted policy and program interventions.

**Methods:** I searched Ovid MEDLINE for peer-reviewed studies that included patients 65 years or older, U.S. hospitals, and an analysis of factors affecting variations in EOL treatment intensity. I categorized these factors based on the socio-ecological framework (SEF).

**Results:** The search produced 23 studies. The SEF individual level factors included age, race, ethnicity, gender, income, advance directives, and written medical orders. The SEF interpersonal factors included patient-doctor familiarity. The SEF community factors included the number of provider connections, primary care-centered networks, area-level competition, percent black admissions, and hospital care intensity level in the area. The SEF institutional factors included providers’ EOL decision-making norms, providers’ EOL treatment styles, organizational norms around do-not-resuscitate (DNR) orders, number of beds and providers, and for-profit compared to public institutions. The SEF policy factors included managed care compared to fee-for-service payment systems.

**Conclusion:** To respond to these factors that explain variations in EOL treatment intensities, training programs for providers on palliative care and EOL conversations should be paired with organizational transformation strategies to affect skills, practices, and cultures. Policymakers should also consider value-based payment policies.

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preface

I would like to thank Gerald Mark Barron, MPH, Amber E. Barnato, MD, MPH, MS, and Nancy D. Zionts, MBA for their guidance, review, insight, and editorial comments.

# Introduction

Even though 86% of Medicare beneficiaries indicate a preference to die at home compared to 9% that would choose to die in the hospital and 5% in a nursing home (Barnato et al., 2007a), about 40% of deaths occur in the hospital and 20% involve services in an intensive care unit (ICU) (Angus et al., 2004). Patients’ treatment preferences are not associated with dying in the hospital (Pritchard et al., 1998). In addition to end-of-life (EOL) care not being aligned with patient preferences, the use of healthcare services in the last 12 months of life consumes about 25% of Medicare spending for inpatient care (Hogan et al., 2001). The extent of these EOL expenditures vary by geography (Goodman et al., 2011).

## Public Health Relevance

If these variations in EOL treatment were aligned with patients’ goals, preferences, and needs, then it may not warrant health policy or public health considerations. However, higher EOL spending areas do not have better outcomes, mortality, quality of care, or patient satisfaction (Fisher et al., 2003), and patient preferences are not associated with variations in EOL spending (Barnato et al., 2007a). One study of hospitals in Pennsylvania found that admission to higher EOL treatment intensity hospitals was associated with post-admission survival gains, but the gains were small, decreased over time, and were not adjusted for quality of life (Barnato et al., 2010). These findings suggest an opportunity to reduce healthcare costs without compromising quality, health outcomes, or adherence to patients’ wishes.

The opportunity to responsibly reduce healthcare costs while improving people’s quality of life warrants the attention of public health. Financial resources that are saved from addressing inefficiencies in healthcare systems can be used for other health-related services. This relevance to public health is heightened when the inefficient treatment practices can cause harm and further deterioration to patients (Krumholz, 2013).

## Current Understanding

The geographical variation in healthcare delivery is a common observation and due to the availability of hospital and physician services (supply), patient characteristics (demand), and differences in physicians’ practice styles (Folland, Goodman, & Stano, 2012). The latter is thought to be influenced by local peers and variations in information between physicians (Folland, Goodman, & Stano, 2012), which creates imperfect understandings of the risks and benefits of treatments. The physicians who perceive the benefit of a treatment to be greater than the true benefit will cause inefficient overutilization of that treatment.

This general explanation of geographical variation matches the empirical evidence of variations in EOL treatment intensity. Higher EOL spending regions have more specialists, hospital beds, ICU beds, technologies, and physicians who are more likely to recommend tests and treatments (Barnato et al., 2007a). There are also differences in decision-making for life-sustaining treatments between low intensity ICUs and high intensity ICUs (Barnato et al., 2012). These market imperfections create opportunities for health policies and programs.

## Objective

To inform the policies and programs, this literature review: (1) identifies published studies that seek to explain the factors associated with variations in EOL treatment intensity in the U.S. among patients 65 years of age or older; (2) synthesizes the findings from these studies using the social-ecological framework (SEF) (Glanz & Bishop, 2010) to categorize the factors; and (3) proposes policy and programmatic responses based on these factors.

As of March 2017, I am unaware of any other literature review on the factors that explain the variations in treatment intensity at the EOL. One review examined the national, regional, inter-hospital, and inter-physician variability of withdrawing life-sustaining treatment in the ICU (Mark et al., 2015). However, this review focused on the withdrawal of life-sustaining treatment, and it did not focus on the factors that explain the variation.

# Methods

I worked with a University of Pittsburgh Health Sciences Librarian to design and refine the following Ovid MEDLINE search in October 2016: end-of-life, terminal care, or end-of-life care; AND critical care or intensive care; AND hospitals, hospital, or academic medical centers; AND retrospective studies, logistic models, cost of illness, cost-benefit analysis, decision making, focus groups, health care costs, health care surveys, health services research, medical staff, hospital, multivariate analysis, proportional hazards models, or comparative analysis.

The search returned 609 articles. I excluded articles if the study cohort included patients less than 65 years of age, if the study included non-U.S. hospitals, and if the study did not include the factors explaining the variations in EOL treatment intensity. I also reviewed the references in the articles that met the inclusion criteria to identify additional peer-reviewed studies, excluding grey literature.

I categorized the primary findings from each article into the different levels of the social-ecological framework (SEF): individual, interpersonal, community, institutional, and policy (Glanz & Bishop, 2010). To address these contributing factors, I offer policy and program responses in the discussion section.

The SEF is used as a systems-thinking approach in public health to explain and understand the interaction of factors at multiple levels that contribute to a population’s health problem or a group’s behavior. In this case, the SEF is used to understand the interaction of factors that explain higher EOL treatment intensity in certain areas. The individual level of the SEF looks at the biological, genetic, racial, ethnic, gender, and personal history of a person. The interpersonal level pertains to the relationships or interactions between individual people. The community level considers the social norms and interactions with groups, networks, and the environment. The institutional level is concerned with the policies, rules, and structure of an organization in the private sector. Finally, the policy level considers the policies, rules, and structures from the public sector.

# Results

The Ovid MEDLINE search produced 14 articles that met the criteria. By reviewing the references in the articles that met the criteria, I identified nine additional articles in the review, bringing the total to 23.

## Characteristics and findings of included studies

Table 1 includes the characteristics of each included article (study year, cohort, design, and primary measures), and Table 2 includes the primary findings of each article. The most common claims databases for calculating EOL treatment intensity measures included the Centers for Medicare & Medicaid (CMS) Part A and B database of fee-for-service Medicare beneficiaries, the Dartmouth Atlas (which uses the CMS databases), and the Pennsylvania Health Care Cost Containment Council (PHC4) database (an all-payer database of hospital admissions in Pennsylvania).

Of the 23 studies, eleven included retrospective case series, ten included an ecologic study design, ten included surveys, two included case studies with interviews, two included a retrospective cohort design, and one included a prospective cohort study (Table 1).

Table 1: Characteristics of Included Studies

| Author | Study Year | Cohort | Design | Measure |
| --- | --- | --- | --- | --- |
| Cher and Lenert, 1997 | 1994 | 81,494 Medicare patients hospitalized in ICUs in California  | Retrospective cohort design | Adjusted potentially ineffective care: in-hospital death or death within 100 days of hospital discharge and total hospital costs above the 90th percentile |
| Pritchard et al., 1998 | 1992-1993 | Patients dying post-hospitalization in the five-hospital, observational SUPPORT study and Medicare beneficiaries who died in 1992 or 1993 | Ecologic study | Percent dying at home or in the hospital |
| Fisher et al., 2003 | Mid-1994 to 1997 CMS claims data for expenditures. Then one-year and five-year sample follow-up data on content, accessibility, and quality of care. | In 306 hospital referral regions (HRRs), Medicare Parts A and B fee-for-service patients hospitalized for hip fracture, colorectal cancer, or acute myocardial infarction (1993-1995) and a representative sample from the 1992-1995 Medicare Beneficiary Survey | Prospective cohort Ecologic study for correlation of aggregate measures | Content, accessibility of care, and quality of care (e.g., preventive services and acute myocardial infarction process measures) with different levels of EOL expenditures  |
| Wennberg et al., 2004 | 1999-2000 | 115,089 Medicare fee-for-service decedents from 77 hospitals on the 2001 US News and World Report list of best hospitals | Retrospective case series of those who died | The last six months of life: number of days spent in hospital and in intensive care units; number of physician visits; percentage of patients seeing 10 or more physicians; and percentage enrolled in hospice |
| Teno et al., 2005 | 1998 Mortality date; survey date unknown | Decedents in high- (n=365) and low-intensity(n=413) hospital service areas | Survey of family members of decedents | Survey-derived information about unmet needs, concerns, and rating of quality EOL care in five domains |

Table 1 Continued

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Author | Study Year | Cohort | Design | Measure |
| Barnato et al., 2007a | March to October 2005 Survey and 2000-2003 CMS Dartmouth Atlas | 2,515 survey responders | Cross-sectional survey Ecological study | EOL Expenditure Index (Medicare spending in last six months of life) |
| Barnato et al., 2007b  | 1989-1999 | Medicare fee-for-service decedents (n=976,220) and survivors (n=845,306) aged 65 or more years old with at least one hospital admission | Retrospective case series of survivors and decedents  | Receipt of ICU admission and intensive procedure over 12 months |
| Barnato et al., 2007c | 2004 Survey2000 and 2004 EOL Intensity Rates | 139 administrative and clinical staff from 11 Pennsylvania hospitals | Survey of staff Ecologic study for correlation of hospital-level measures | Survey-derivedperceptions of hospital's norms of EOL decision making and treatment |
| Lin et al., 2009 | April 2001-March 2005 PHC4 and June 2005-May 2006 survey | 124 hospitals in Pennsylvania completed the survey | Survey of chief nursing officersRetrospective cohort of patients with high probability of dyingEcologic study for correlation of hospital-level measures | Hospital-level observed-to-expected ratios of ICU admission, ICU length of stay, and life-sustaining treatment use among admissions with a high probability of dying Survey information about hospital and ICU programs, policies, or practices |
| Smith et al., 2009 | 1992 to 1999 | 40,960 Medicare fee-service decedents with advanced cancer | Retrospective case series of those who died with advanced cancer | Percent enrolled in hospice, hospitalized two or more times in the last month of life, spent more than 14 days hospitalized in the last month of life, admitted to the intensive care unit in the last month of life, or died in the hospital |

Table 1 Continued

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Author | Study Year | Cohort | Design | Measure |
| Teno et al., 2010 | 2000-2007 | 2,797 hospitals with at least 30 admissions of nursing home residents with advanced cognitive impairment (280,869 admissions among the 163,022 nursing home residents) | Ecologic study  | Rate of feeding tube insertion  |
| Kaplan, 2011 | Deaths in 2004-2005 and two year follow-up period | Medicare fee-for-service in last two years of life  | Retrospective case series of those who died Ecologic study for correlation of aggregate measures | Ratios of Medicare costs in last two years of life  |
| Kelley et al., 2011 | 2000 to 2006 | 2,394 Medicare fee-for-serve decedents linked to the Health and RetirementStudy (HRS) survey | Prospective surveyRetrospective case series of those who died | Medicare expenditures in the last 6 months of life |
| Kwok et al., 2011 | 2007-2008 | 1,8020,29 Medicare fee-for-service decedents | Retrospective case series of decedents Ecologic study for correlation of aggregate measures  | End-of-life surgical intensity score (proportion of decedents who received surgical procedure during last year of life) |
| Nicholas et al., 2011 | 1998-2007  | 3,302 Medicare fee-for-serve decedents linked to the HRS survey  | Prospective surveyRetrospective case series of those who died | Medicare expenditures, life-sustaining treatments, hospice care, and in-hospital death in the last 6 months of life |
| Zheng et al., 2011 | 2005-2007 | 49,048 long-term care residents in 555 New York State nursing homes who died in the hospital based on Medicare inpatient and hospice claims | Retrospective case series of decedents | Hospice use and in-hospital death within eight days of nursing home transfer  |

Table 1 Continued

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Author | Study Year | Cohort | Design | Measure |
| Barnato et al., 2012 | 2008-2009 | Observed 80 and 73 patients. Interviewed 23 and 26 staff and three and four patients and families at a low intensity academic medical center (AMC) and high intensity AMC, respectively. | Mixed methods case study ateach AMC | Patterns of decision making regardinginitiation, continuation, and withdrawal of life-sustaining treatment  |
| Barnett et al., 2012 | 2006 CMS encounter data, 2006 American Medical Association (AMA) and American Hospital Association (AHA) descriptive data, and 2001-2005 Dartmouth Atlas cost and intensity data | 2.6 million Medicare Part A and B fee-for-service patients hospitalized for one of nine life-threatening conditions in the last two years of life (61,146 physicians associated with 528 hospitals) | Retrospective case series of Medicare fee-for-service patients hospitalized at least once in last two years of lifeEcologic study for correlation of aggregate measures | Hospital-level spending (three measures) and intensity (six measures) in the last two years of life |
| Miesfeldt et al., 2012 | 2003 to 2007 | 235,821 Medicare fee-for-service cancer decedents | Retrospective case series of those who died with cancer | Proportion with more than one hospitalization or ER visit in the last 30 days of life, an admission to ICU in the last 30 days, a death in an acute care hospital, chemotherapy in the last 14 and 30 days of life, no admission to hospice within the last 6 months of life, and admission to hospice within 3 days of death |

Table 1 Continued

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Author | Study Year | Cohort | Design | Measure |
| Baker et al., 2014 | 2005 survey, 2005 mortality and spending data, and 2016 supply data from the Dartmouth Atlas | 4,000 Medicare fee-for-service decedents | Cross-sectional surveyEcological study | Medicare spending and preferences around physicians, health status, and health care in the last six months of life across HRRs |
| Barnato et al., 2014 | 2009 | 48 physicians from two AMCs, using two standardized actors of a critically ill 78 year old with metastatic gastric cancer | Mixed methods interview and survey of physicians based on a simulated case | Treatment plan, prognosis, diagnosis, case perceptions, and clinical reasoning across AMCs |
| Tschirhart et al., 2014 | 2002 to 2008 HRS linked to Medicare fee-for-serve claims | 3,069 HRS decedents over age 65 linked to Medicare claims | Prospective surveyRetrospective case series of those who died | The proportion of decedents who received intubation and mechanical ventilation, tracheostomy, gastrostomy tub insertion, enteral and parenteral nutrition, or cardiopulmonary resuscitation in the last six months of life |
| Hart et al., 2015 | April 1, 2011 to December 31, 2008 (Project IMPACT ICU clinical information system) | 277,693 ICU patient visits in 141 ICUs in 105 hospitals  | Retrospective cohort survey | Among ICU patients with limitations on life-sustaining treatments, the proportion who received cardiopulmonary resuscitation, new forms of life support, and the addition or reversal of treatment limitations |

Table 2: Primary Findings of Included Studies

|  |  |
| --- | --- |
| Author | Primary Findings |
| Cher and Lenert, 1997 | The occurrence of potentially ineffective care was less common among Medicare managed care beneficiaries than Medicare fee-service beneficiaries (adjusted odds ratio [AOR] of 0.75 [95% CI 0.65-0.87]). |
| Pritchard, 1998 | The percent dying in-hospital varied from 23% to 54% across U.S. Hospital Referral Regions (HRRs). The risk of in-hospital death increased for residents of regions with greater hospital bed availability and use. In contrast, the risk of in-hospital death decreased in regions with greater nursing home and hospice availability and use. |
| Fisher et al., 2003 | Higher-spending quintiles had more hospital beds and physicians, a higher proportion of large hospitals, teaching hospitals, and urban residents, more black patients, and more patients in the highest and lowest income categories. |
| Wennberg et al., 2004 | Among 77 hospitals, the days in hospital per decedent ranged from 9.4 to 27.1. The days in intensive care units ranged from 1.6 to 9.5. The number of physician visits ranged from 17.6 to 76.2. The percentage of patients seeing 10 or more physicians ranged from 16.9% to 58.5%. And hospice enrollment ranged from 10.8% to 43.8%. Potential explanations include variation in bed and workforce supply. |
| Teno et al., 2005 | Decedents in the lower-ICU-use hospital service areas (HSAs) were more likely to have completed a formal advance directive (79.3% vs 61.0%; p=.06) and expressed wishes for care (71.4% vs 61.9; p=.05). Respondents from high-intensity HSAs were more likely to report inadequate emotional support for the decedent (risk ration [RR] of 51.2 [95% CI 51.0–1.4]), concerns with shared decision-making (RR 51.8 [95% CI 51.0–2.9]), inadequate information about what to expect (RR 51.5 [95% CI 51.3–1.8]), and failure to treat the decedent with respect (RR 51.4 [95% CI 51.0–1.9]). In the higher-ICU-use regions, the average quality rating for EOL care was 2.7 points below the average rating in the lower-ICU-use regions. |
| Barnato et al., 2007a | When the lowest spending quintile was compared to the highest, there were no differences in regard to: (a) concern about getting too little treatment (39.6% vs. 41.2%; p=0.637) or too much treatment (44.2% vs. 45.1%; p=0.797) at the end of life, (b) preference for spending last days in a hospital (8.4% vs. 8.5%; p=0.965), (c) preferences for potentially life-prolonging drugs that made them feel worse all the time (14.4% vs.16.5%; p=0.326), (d) preferences for palliative drugs (77.7% vs. 73.4%; *p=*0.138), and (e) preferences for mechanical ventilation (21% vs. 21.4%; p=0.870 if it would extend their life by 1 month). |
| Barnato et al., 2007b | Black decedents were not more likely than non-blacks to be admitted to the ICU during the last 12 months of life (AOR 1.0 [95% CI 0.99-1.03]), more likely to be admitted to the ICU during the terminal hospitalization (AOR 1.03 [95% CI 1.0-1.06]), and more likely to receive an intensive procedure during the last 12 months of life (AOR 1.1 [1.08-1.14]) and terminal hospitalization (AOR 1.23 [1.20-1.26]). However, blacks’ hospital access and choice may mediate the observed relationship. In comparison, black survivors were less likely than non-blacks to be admitted to the ICU (AOR 0.93 [0.91-0.95]) and to receive an intensive procedure (AOR 0.72 [0.70-0.73]).  |
| Barnato et al., 2007c | Of the four factors surveyed among hospital staff, only patient-doctor familiarity was inversely correlated with terminal ICU admission (p<0.001) and mechanical ventilation (p=0.03). The four factors survey included staff perceptions of informal norms around life prolongation, palliation, shared decision-making, and patient-doctor familiarity. Staff responses varied more between hospitals than within hospitals (p≤0.03).  |

Table 2 Continued

|  |  |
| --- | --- |
| Author | Primary Findings |
| Lin et al., 2009 | The following factors were independently associated with greater EOL treatment intensity at the alpha level of 0.05 and explained about 50% of the total variation in EOL treatment intensity: hospital bed size, percent of admissions comprised of black patients, area-level competition, and the presence of an ICU long length of stay review committee. These factors were stronger predictors of intensity than hospital programs, policies, or practices. |
| Smith et al., 2009 | The hospice enrollment percentages included 42.0% for white patients, 36.9% for black patients, 32.2% for Asian patients, and 37.7% for Hispanic patients. The hospitalized percentages included 11.7%, 15.0%, 13.7% for black, Asian, and white patients, respectively. The percentages admitted to the ICU in the last month of life included 12.0%, 17.0%, and 16.2% for black, Asian, and white patients, respectively. The percentages who died in the hospital included 26.5%, 31.3%, 33.7% for black, Asian, and white patients, respectively. These differences remained after adjustment.  |
| Teno et al., 2010 | Higher feeding tube insertion rates were associated with the following hospital features: for-profit ownership vs. government owned (AOR 1.33 [95% CI 1.21-1.46]), 310 beds vs. 101 beds (AOR 1.48 [1.35-1.63]), and greater ICU use in the last 6 months of life when the highest and lowest decile were compared (AOR 2.60 [2.20-3.06]). Levels of specialty care and hospice care were weakly or not associated with rates of feeding tube insertion. Blacks and Hispanics were more likely to undergo a feeding tube insertion (AOR 1.96 [1.89-2.04] and AOR 1.36 [1.27-1.46], respectively). The following directives and orders were associated with lower rates of feeding tube insertions: advance directive living will, advance directive durable power of attorney for health care, written do-not-resuscitate (DNR) order, and written order to forgo artificial hydration and nutrition (AOR 0.75 [0.70-0.79], 0.88 [0.84-0.91], 0.65 [0.62-0.67], and 0.73 [0.67-0.80], respectively). |
| Kaplan, 2011 | In San Diego, 44.6% of decedents were enrolled in hospice during the last 6 months of life compared to 22.4% in Los Angeles, which had 30% more acute hospital beds. |
| Kelley et al., 2011 | The following were associated with higher Medicare expenditures in the last six months of life: decline in function (RR of 1.64 [95% CI 1.46 to 1.83]), Hispanic ethnicity (RR of 1.50 [1.22 to 1.85]); black race (RR of 1.43 [1.25 to 1.64]); certain chronic diseases; EOL practice patterns (RR of 1.09 [1.06 to 1.14]), and hospital beds per capita (RR of 1.01 [1.00 to 1.02]). And the following were associated with lower Medicare expenditures: nearby family (RR of 0.90 [0.82 to 0.98]) and dementia (RR of 0.78 [0.71 to 0.87]). Advance care planning had no association.  |
| Kwok et al., 2011 | Compared to decedents who did not undergo surgery, decedents who underwent surgery were younger (82.5 years old vs. 79.8 years old), more often men, and more often non-white. Patients who underwent a surgical procedure more often had a Charlson Comorbidity Index of 3 or more. There were positive correlations with hospital referral region (HRR) adjusted death rates (r=0.13; p=0.03), hospital beds (r=0.37; p<0∙0001), and Medicare reimbursements (r=0.50; p<0∙0001). |
| Nicholas, et al., 2011 | In high-spending HRRs, advance directives that specified limits in care were associated with lower spending (-$5,585 per decedent [95% CI -$10,903 to -$267), lower adjusted probabilities of in-hospital death (-9.8% [-16% to -3%]), and higher adjusted probabilities of hospice use (17% [11% to 23%]). |

Table 2 Continued

|  |  |
| --- | --- |
| Author | Primary Findings |
| Zheng et al., 2011 | Blacks are more likely than whites to die in the hospital (odd ratio (OR) 2.05 [95% CI 1.92–2.19]). Blacks are less likely than whites to use hospice (OR 0.65 [0.58–0.71]). More black residents have feeding tubes compared with whites (31.12% vs. 10.08%). Fewer blacks have DNR or do-not-hospitalize orders than whites(41.21% vs. 75.45% and 2.61% vs. 7.82%, respectively). Within the same facility, there were no racial disparities in in-hospital death (OR 0.95 [0.87–1.04]) or hospice use (OR 0.90 [0.79–1.02]).  |
| Barnato et al., 2012 | The low-intensity academic medical center was more likely to use a time-limited trial of life-sustaining treatment followed by withdrawal (27% vs. 8%; p=0.01) and to have a known outcome of death (31% vs. 4%; p=0.001). Between the low- and high-intensity ICUs, there were qualitative differences in goals of life-sustaining treatment, the determination of dying, concern about harms of commission versus omission, and physician self-efficacy for life-sustaining decision-making.  |
| Barnett et al., 2012 | A one standard deviation increase in the median number of connections per physician at an average-sized urban hospital was associated with a 17.8% increase (95% CI 13.2-22.25) in Medicare spending, 17.4% (95% CI 12.6-22.4) increase in hospital days, and 23.8% (95% CI 18.6-29.1) increase in physician visits. In contrast, a one standard deviation increase in the centrality of primary care was associated with a 6.0% (-9.5 to -2.4) lower overall spending, 9.2% (-13.1 to -5.1) lower spending on imaging, and 12.9% (-13.1 to -5.1) lower spending on tests.  |
| Miesfeldt et al., 2012 | Older age (≥ 75 vs 66-75) was associated with lower ORs of 0.49 to 0.89 for aggressive care and a lower OR of 0.92 [95% CI 0.89-0.95] for late hospice enrollment. Female gender was associated with lower ORs of 0.82 to 0.86 for aggressive care, and an OR of 0.84 [0.81-0.8] for late hospice enrollment. Black race was associated with higher ORs of 1.08 to 1.38 for aggressive acute care, a lower OR of 0.76 [0.71-0.81] for late chemotherapy, and a lower OR of 0.81 [0.76-0.86] for late hospice enrollment. |
| Baker et al., 2014 | Supply factors (e.g., the number of physicians, specialists, and hospital beds) explained 23% of Medicare spending variation across HRRs, patients’ health and income explained 12%, and patients’ preferences explained 5%. Relative to these factors, patients’ preferences explained the largest share of variation in end-of-life spending when the relative importance of preferences was explored for spending at the end of life, inpatient spending, and spending on physician services.  |
| Barnato et al., 2014 | Treatment decisions, diagnosis, and prognosis between the high and low-intensity academic medical centers (AMC) did not significantly differ. However, case perceptions at the low-intensity AMC appeared to be influenced by the absence of a DNR order, and at the high-intensity AMC, the case perceptions appeared to be influenced by the patient’s critical illness. The low-intensity AMC had norms of universal code status discussion and documentation, whereas the high-intensity AMC had norms of oncologists’ avoiding code status discussions.  |
| Tschirhart et al., 2014 | A lower adjusted odds ratio (AOR) of an intensive procedure was significantly associated with 85–94 year olds vs. 65-74 year olds (AOR 0.67 [95% CI 0.51–0.90]), Alzheimer’s disease (AOR 0.71 [0.54–0.94], cancer (AOR 0.60 [0.43–0.85]), nursing home residence (AOR 0.70 [0.50–0.97]), and having an advance directive (AOR 0.71 [0.57–0.89]). A higher AOR was significantly associated with living in a region with higher hospital care intensity (AOR 2.16 [1.48–3.13]) and black race (AOR 2.02 [1.52–2.69]). Hospital beds per capita did not significantly affect the odds of undergoing an intensive procedure.  |

Table 2 Continued

|  |  |
| --- | --- |
| Author | Primary Findings |
| Hart et al., 2015 | After risk adjustments, across the ICUs, the proportion of patients admitted with treatment limitations who: received cardiopulmonary resuscitation ranged from 3.8% to 92.4% (median of 37.7%), received new forms of life support ranged from 6.0% to 84.2% (median of 30.0%), survived and had new treatment limitations established ranged from 1.9% to 57.3% (median of 11.2%), and survived and had reversal of treatment limitations during or following ICU admission ranged from 1.8% to 76.2% (median of 20.2%). |

## Factors contributing to higher EOL Treatment InTensity

Table 3 categorizes the factors from Table 2 that affected higher EOL treatment intensity into the following levels of the social-ecological framework (SEF) from the perspective of the patient: individual, interpersonal, community, and institutional. Although individual, patient-level factors are likely confounding variables of geographical variation, these factors are included to provide a comprehensive list of all of the factors that have been associated with higher EOL treatment intensity in the included studies.

Table 3: Factors Affecting Higher EOL Treatment Intensity, by Social-Ecological Framework Level

|  |  |
| --- | --- |
| Social-Ecological Framework (SEF) Level | Factors Affecting Higher EOL Treatment Intensity |
| Individual1 | * Younger age
* Female
* Blacks, Hispanics, and Asians2
* Highest or lowest income bracket
* Use or evidence of: advance directive living will, advance directive durable power of attorney for health care, advance directives that specific limits in care, written do-not-resuscitate (DNR) order, and written order to forgo artificial hydration and nutrition (these factors affect lower EOL treatment intensity)
 |
| Interpersonal3 | * Lack of patient-doctor familiarity
* Not having nearby family
 |
| Community4 | * Hospital doctors with more connections to providers
* Hospitals without primary care-centered networks
* Area-level competition
* Percent of hospital admissions from black patients
* Region with a higher hospital care intensity level
 |
| Institutional5 | * Providers’ EOL decision-making norms at different medical centers
* Providers’ EOL treatment styles at different medical centers
* Organizational norms around avoiding DNR status discussions (compared to norms about universal DNR code status discussion and documentation)
* More hospital beds6 and providers
* For-profit compared to government-owned
 |
| Policy6 | * Fee-for-service compared to managed care
 |

1 The individual SEF level includes personal factors, such as health history, race, ethnicity, and biological factors.

2 Race and ethnicity factors may be mediated by access to and choice of hospitals, since within-hospital effects have not been observed for racial differences (Barnato et al., 2006).

3 The interpersonal SEF level includes relationships between people and peer influence.

4 The community SEF level includes social networks and social norms in the community.

5The institutional SEF level includes rules, regulations, structures, and norms of institutions.

6 The policy SEF level includes local, state, and federal policies.

The articles also described several factors that do not affect higher EOL treatment intensity. Barnato et al. did not find significant differences regarding patient preferences when comparing the lowest spending quintile regions to the highest spending quintile regions (Barnato et al., 2007a), and Baker et al. found that patient preferences only explain five percent of Medicare spending variation in the last six month of life across hospital referral regions (HRR) (Baker et al., 2014). Also, Lin et al. reported that most of the hospital programs, policies, and practices that were significantly associated with EOL intensity in univariable models were not significant in multivariable models (Lin et al., 2009).

# Discussion

Based on the 23 studies of EOL treatment intensity variation in the U.S. that reported potential causes of the variation, the SEF individual level factors included age, race, ethnicity, gender, income, advance directives, and medical providers’ written orders. The SEF interpersonal level factors included patient-doctor familiarity. The SEF community level included the number of provider connections, primary care-centered networks, area-level competition, percent black admission, and hospital care intensity level in the area. The SEF institutional level included providers’ EOL decision-making norms, providers’ EOL treatment styles, organizational norms around DNRs, number of beds and providers, and for-profit compared to public institutions. The SEF policy level included managed care compared to fee-for-service payment systems.

## Policy and Program Goals

In response to these factors, policies and programs should be designed to increase the effective use of advance directives and written orders and change local norms and practice styles about EOL decision-making. I selected these goals, since they target the most amendable factors in Table 3 that affect EOL treatment intensity.

In this section, I propose programs and policies to address these factors. These programs should ensure the engagement of different racial groups in the design and operation of the program, since blacks are less likely to use hospice, are more likely to die in hospitals with greater EOL ICU (Barnato et al., 2006), and are more likely to prefer life-sustaining treatments than whites (Barnato et al., 2009). The proposed policies that target local norms of practice styles in hospitals may also impact this racial disparity, because the disparity is primarily due to a between-hospital effect as opposed to a within-hospital effect, meaning that blacks tend to use hospitals with higher EOL intensity (Barnato et al., 2006). Thus, impacting the norms and practice styles in a hospital could reduce disparities.

## Programs

Hospitals and healthcare education programs should develop EOL training programs to address the goals around advance directives, written orders by medical providers, and EOL local norms and practice styles. Healthcare providers are not adequately trained in palliative care or EOL conversation skills (National Academy of Sciences, 2015). This is an appropriate time to design training program for these skills, since as of January 1, 2016, physicians can bill Medicare CPT codes 99497 and 99498 for advance care planning discussions (CMS Medicare Learning Network, 2016).

At a minimum, the training programs should cover palliative care principles, advance directives, Physician Orders for Life-Sustaining Treatment (POLST), and EOL conversation skills. These topics relate to the factors that explain variations in EOL treatment intensities. In addition, evidence suggests the following: palliative care improves quality of life and reduces healthcare costs (Smith et al., 2014), EOL communication skills can be effectively taught to healthcare professionals (National Academy of Sciences, 2015), advance care planning improves the alignment between the type of care preferred and type of care delivered (Weathers et al., 2016; Houben et al., 2014), POLST forms increase the likelihood of treatment preferences being documented as orders (Hickman et al., 2010), and POLST orders restricting medical treatments are associated with fewer life-sustaining treatments (Hickman et al., 2010).

These training programs should also cover best practices and standards for creating an EOL culture in organizations that honors patients’ preferences, goals, and values. According to the National Academy of Sciences, incentives, quality standards, and system supports are needed to facilitate improved EOL conversation skills in organizations. Knowing these best practices for promoting improved EOL conversations, would enable healthcare providers to know what they should expect from an organization that honors patient’s EOL goals. With this knowledge, providers would be empowered to question why these organizational best practices are not being adhered to in their work environment.

These training topics could be required by graduate education oversight bodies, certifying bodies, and state licensing bodies for nurses, physicians, occupational therapists, social workers, pharmacists, and chaplains who are part of the team offering palliative care and EOL treatment (National Academy of Sciences, 2014). For healthcare providers who are already in the workforce, organizations should require and recommend educational modules in their learning management systems.

However, training alone will likely not be sufficient to change local norms and practice styles around EOL decision-making in organizations. While training can increase knowledge, additional support within the work setting is often needed to demonstrate and apply new skills in practice settings (Fixsen et al., 2005). Implementation science suggests that certain components of implementation are needed to translate evidence-based concepts into practice. The implementation framework from Fixsen et al. includes: staff selection, training on the new skill, coaching to perform and improve the new skill, evaluation to guide decision-making and improvement, administrative supports to ensure leadership engagement, and systems interventions to secure appropriate resources (Fixsen et al., 2005). This framework helps to account for the organizational context in which the best practices is implemented in and influences from the external environment.

As a result, healthcare organizations should deploy an organizational transformation strategy to change the organizational structures and cultures that influence the routine use of new skills and behaviors. Based on the implementation framework, this transformation strategy could include leadership support, tracking systems, provider champions, and ongoing skill development. The CEOs and department chairs can communicate, reinforce, and demonstrate the organization’s values and norms around EOL care. To target the organization’s training and education plans, organizations can also track which providers have been exposed to the core EOL training topics, and which still need introductory trainings.

Each discipline of providers in organizations should also designate EOL champions who are respected among their peers in the organization. These champions would be responsible for providing ongoing coaching to their peers on palliative care principles and EOL communication skills and for talking with their peers who display EOL practice styles that fall outside of the organization’s norms. The coaches could model their interactions with their peers based on the health belief model, which is used to change people’s behavior by exploring and strengthening their perceptions of susceptibility, severity, benefits, barriers, and self-efficacy (Glanz & Bishop, 2010).

## Policies

Implementation science suggests that the use of new evidence-based practices are influenced by sociopolitical factors, including funding (Fixsen et al., 2005). As a result, it is necessary to consider health policy changes to support the uptake of the evidence-based EOL skills.

The continued movement from a payment system that rewards volume (fee-for-service) to a system that rewards value presents opportunities to reduce variations in EOL treatment intensity that are not aligned with patients’ preferences (National Academy of Sciences, 2015). The National Academy of Sciences’ report, “Variation in Health Care Spending,” also recommended to test and evaluate payment reforms (National Academy of Sciences, 2013).

This transition is beginning with pay-for-performance models and shared savings. Pay-for-performance models adjust payments if certain clinical targets are met, and shared savings distributes a portion of the savings back to the network of providers if certain quality and cost control goals are achieved for a defined population. Shared savings has been shown to reduce costs in the Medicare system (CMS, 2014; Hoangmai et al., 2014), and although the evidence for pay-for-performance methods is mixed, its effectiveness is largely dependent on the context, design, type of incentives, the baseline performance levels, and the criteria of quality measurements (Van Herck et al., 2010).

In response, state and federal policymakers and administrators should consider including EOL quality measures in pay-for-performance contracts, shared savings contracts, and public reporting systems (e.g., CMS’ Hospital Compare website). Two potential measures include “percentage of patients with chart documentation of preferences for life sustaining treatments” (C) and “patients admitted to ICU who have care preferences documented” (National Quality Forum no. 1626) (AHRQ, 2014). Including these measures in payment contracts will help gain the attention of healthcare administrators who could in turn help providers adopt the skills and processes for eliciting and following through with patients’ EOL treatment preferences.

However, both pay-for-performance and shared savings payment models are only augmenting an underlying fee-for-service system that still effects the daily behaviors of providers and organizations. As a result, research is needed to study the effect of shared savings models on variations in EOL treatment intensities.

Demonstrations can also be designed to test whether risk-adjusted capitated payments to providers and hospitals affect variations in EOL treatment intensities compared to fee-for-service arrangements. There is some evidence to suggest that these types of managed care policies may reduce potentially ineffective care (Cher and Lenert, 1997), and most studies conclude that in capitation payment models, physicians provide less services without compromising quality of care (Kongstvedt, 2013). However, given the healthcare needs of older patients, capitated payment models must be appropriately risk-adjusted and not limited to the end-of-life phase.

States can also codify POLST orders into law and create committees to review and update the POLST forms in the State. These forms are used to document patients’ preferences for life-sustaining treatments based on a conversation between a physician and a patient with advanced illness or a serious health condition. If state laws codify these orders, then providers would need to adhere to the patient’s EOL goals and preferences in the POLST form regardless of the setting of care.

## Conclusion

This review categorized the factors of variations in EOL treatment intensity and proposed policy and program interventions. The review identified factors at the individual, interpersonal, community, institutional, and policy level that explain the variation.

To respond to these factors, healthcare organizations and the bodies that oversee healthcare education programs should include curricula to increase the effective use of advance directives and POLST forms. At the same time, healthcare organizations should deploy a transformation strategy to affect the organizational culture and norms around EOL decision-making and treatment. This includes leadership support, tracking systems, provider champions, and ongoing skill development. To support his work, policymakers should continue to transition from a payment system that rewards volume to a system that rewards value. This will move the healthcare system towards a system that is based on the goals, preferences, and needs of patients.

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