

Gap in Knowledge: Advanced Care Planning

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Project Overview

Conduct literature reviews to assess the utilization of advanced care planning in end of life care for patients with neurological disorders.

Sought to identify what literature said about the use of advanced care planning
Medicare codes

Context: The Importance of Context at EOL Service

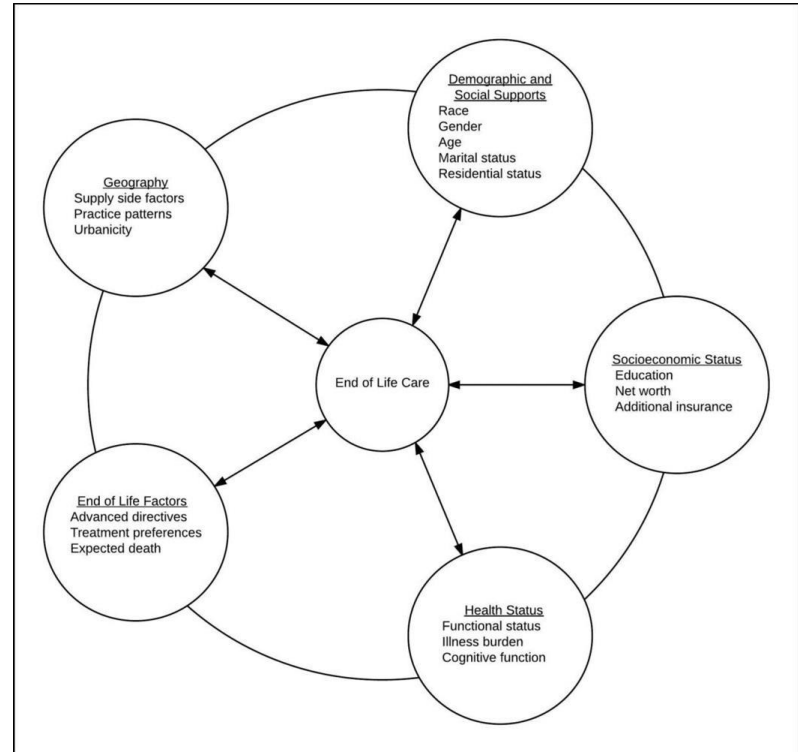


Figure 1 Modeling Framework for Factors Contributing to Differences in End-of-Life Care

Our Roles in the Project

Andrew

Look through the RESDAC files to identify labels to differentiate healthcare centers

Shared Tasks

Conducted a literature review on the EOL and other qualities to identify gaps in knowledge

Miguel

Created table that summarizes findings from literature review

Methods

- Began by reading the background literature that was provided
- Reviewed Medicare data videos on RESDAC to understand how the data is used.
- Literature review was done through the use of specific search terms (i.e. medicare advanced care planning) on both PubMed and the Dartmouth Atlas Website
 - Uploaded papers to shared drive along with a summarization of each article

Implication of Findings (Andrew)

Based on a Systematic Review, EOL care differences among ethnic/racial minority cancer patients were found in the processes, preferences, and beliefs regarding their care. The influence could be religious or cultural differences, caregiver respect for patient autonomy, access barriers, and knowledge of EOL care option (Melissa 2016)

Based on ongoing population-based cohort study with enrollment between January 25, 2003, and October 3, 2007, once the cause of analyses were adjusted, African American participants were significantly less likely to use 3 or more days of hospice and likely to use emergency department visits and hospitalizations and undergo intensive treatment) in the last 6 months of life compared with White decedents.

Expenditures

- In a Retrospective cohort study. The expenditure of the last 6 months of life between social groups was examined. Average EOL Medicare expenditures were \$13,522 more for black decedents and \$16,341 more for Hispanics.
- Controlling for demographic, socioeconomic, geographic, medical, and EOL-specific factors, the Medicare expenditure fell to \$8,047 more for black and \$6,855 more for Hispanic



However, up to 85% of the observed higher costs for nonwhites are accounted for after looking at their greater end-of-life use of the intensive care unit and various intensive procedures (For Example, gastrostomies, used by 10.5% of blacks, 9.1% of Hispanics, and 4.1% of whites).

Findings (Miguel)

- A) Main finding was that there is a gap in knowledge when it comes to Medicare advanced care planning use for patients with neurological disorders. More research needs to be done in order to fully understand the complexities of end of life care for these individuals.
- B) Existing literature suggests that people with neurological disorders do not engage providers in advanced care planning talks - but that it could potentially reduce family stress, anxiety, and depression.
- C) One paper looked at creating and testing neurological disorder specific measures to assess EOL preferences

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> [J Neurol](#). 2019 Oct;266(10):2406-2422. doi: 10.1007/s00415-019-09417-7. Epub 2019 Jun 12.

End-of-life measures in Huntington disease: HDQLIFE Meaning and Purpose, Concern with Death and Dying, and End of Life Planning

Noelle E Carlozzi ¹, Nicholas R Boileau ², Jane S Paulsen ^{3 4 5}, Joel S Perlmutter ⁶, Jin-Shei Lai ⁷, Elizabeth A Hahn ⁷, Michael K McCormack ^{8 9}, Martha A Nance ^{10 11}, David Cella ^{7 12 13}, Stacey K Barton ⁶, Nancy R Downing ¹⁴

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Lessons Learned

Andrew

- Understanding how the gaps in Advance Care Planning could be understood through the lens of Social Context
- Learned about identifying parameters of Resdac and obtaining information from databases

Miguel

- Gained more insight into the complexities that come with end of life care
- Learned about how Medicare data is collected and used

Resources

[Racial and Ethnic Differences in End-of-Life Medicare Expenditures - PubMed \(nih.gov\)](#)

[End-of-Life Care for People With Cancer From Ethnic Minority Groups: A Systematic Review - PubMed \(nih.gov\)](#)

[Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort - PubMed \(nih.gov\)](#)

[Current research findings on end-of-life decision making among racially or ethnically diverse groups](#)

[End-of-life care for people with dementia from ethnic minority groups: a systematic review](#)

[Cultural diversity and barriers to high-quality end of life care](#)

Thank You

Allison Willis

Joanne Levy and Joanna Kim

SUMR Cohort