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Closing the Gap in Hospice Utilization for the Minority Medicare Population

M. Courtney Hughes, PhD, MS1,2 and Erin Vernon, PhD, MA3

Abstract

Background: Medicare spends about 20% more on the last year of life for Black and Hispanic people than White people. With lower hospice utilization rates, racial/ethnic minorities receive fewer hospice-related benefits such as lesser symptoms, lower costs, and improved quality of life. For-profit hospices have higher dropout rates than nonprofit hospices, yet target racial/ethnic minority communities more through community outreach. This analysis examined the relationship between hospice utilization and for-profit hospice status and conducted an economic analysis of racial/ethnic minority utilization. Method: Cross-sectional analysis of 2014 Centers for Medicare & Medicaid Services (CMS), U.S. Census, and Hospice Analytics data. Measures included Medicare racial/ethnic minority hospice utilization, for-profit hospice status, estimated cost savings, and several demographic and socioeconomic variables. Results: The prevalence of for-profit hospices was associated with significantly increased hospice utilization among racial/ethnic minorities. With savings of about $2,105 per Medicare hospice enrollee, closing the gap between the White and racial/ethnic minority populations would result in nearly $270 million in annual cost savings. Discussion: Significant disparities in hospice use related to hospice for-profit status exist among the racial/ethnic minority Medicare population. CMS and state policymakers should consider lower racial/ethnic minority hospice utilization and foster better community outreach at all hospices to decrease patient costs and improve quality of life.

Keywords
hospice, Medicaid/Medicare, health care disparity, race/ethnicity

Introduction

On average, one quarter of individual Medicare expenditures take place during the patient’s last year of life (Riley & Lubitz, 2010), with end-of-life Medicare costs for Black people exceeding those for White people by 20% (Byhoff, Harris, Langa, & Iwashyna, 2016). Several studies have examined why such racial disparities in spending exist, pointing some of the causes to geographic, sociodemographic, and morbidity differences (Baicker, Chandra, Skinner, & Wennberg, 2004; Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009; Kelley et al., 2011). Through patient interviews, Martin et al. (2011) found racial/ethnic minorities were more likely than White people to expend their financial resources to extend life. Medicare expenditure data showed Black and Hispanic people were significantly more likely than White people to be admitted to the intensive care unit. Black people were also more likely to receive more intensive procedures such as resuscitation and cardiac conversion, mechanical ventilation, and gastrostomy for artificial nutrition (Hanchate et al., 2009).

An alternative to pursuing costly, life-sustaining strategies for terminally ill patients is enrolling in hospice. Hospice care uses a team-oriented medical approach and emphasizes pain management and emotional support for the patient with a life expectancy of 6 months or less. Most hospice care takes place in the patient’s home (56% of hospice care) or a nursing facility (42% of hospice care) (National Hospice and Palliative Care Organization, 2018) and provides support to the patient’s family. Benefits from such care include lower costs, lesser symptoms, and a higher quality of life (Institute of Medicine, 1997; Kelley, Deb, Du, Aldridge Carlson, & Morrison, 2013; Steinhauser et al., 2000). Two surveys conducted by Gallup 4 years apart both showed 9 out of 10 terminally ill patients with less...
than 6 months to live would prefer to be cared for at home (Institute of Medicine, 1997). American Hospice Foundation (n.d., para. 2) cites two common reasons patients choose hospice care: (a) to stay at home and (b) avoid curative treatments that are painful or require hospitalization.

A recent analysis of Medicare’s new payment structure that began in January 2016 showed hospice enrollment would still provide the potential for cost savings. Medicare’s new payment structure, designed to align payments with service costs and ensure quality care in the last days of life, consists of a two-tiered per diem structure with payments increasing through Days 1 to 60 then decreasing for Days 61 and beyond. The last 7 days of life may have add-on payments retrospectively (Taylor et al., 2018).

Racial/ethnic minority hospice utilization has been found to be lower than that of the White population (Haines et al., 2018; Hardy et al., 2011; Ramey & Chin, 2012) when controlling for other socioeconomic factors such as income, area population, education, and age. Pan, Abraham, Giron, LeMarie, and Pollack (2015) showed Asian and Hispanic people were less familiar than White people with hospice services. In that study, most of the Asian and Hispanic respondents were open to receiving information about hospice in the future and reported they would tell friends and family members about hospice (Pan et al., 2015). One variable that relates to a greater number of racial/ethnic minorities receiving information about hospice is hospice ownership status. For-profit hospices tend to engage in greater community outreach to low-income and racial/ethnic minority communities than nonprofit hospices (Aldridge et al., 2014; Stevenson, Grabowski, Keating, & Huskamp, 2016). Stevenson et al. (2016) found this relationship persisted despite its chain status. With the growth in the proportion of hospices having for-profit ownership from 5% in 1990 to over 60% in 2014, it is important to compare measures such as utilization between hospices with different ownership status.

This study compares hospice utilization by racial/ethnic minorities between for-profit and nonprofit hospices, examining whether there is an association between the proportion of Medicare racial/ethnic minority patients enrolling in hospice per state and the proportion of for-profit hospices in that state. Also included are estimated projected cost savings if racial/ethnic minority Medicare hospice utilization levels were to increase to that of the White Medicare hospice utilization levels.

**Method**

**Data Sources**

The 2014 hospice utilization data were obtained from the Centers for Medicare & Medicaid Services (CMS) Chronic Conditions Data Warehouse (CCW; 2018), a database that has 100% of Medicare enrollment and fee-for-service claims data. CCW was launched to aid researchers in analyzing CMS data to help improve quality of care, decrease health care costs, and curb medical utilization for chronically ill Medicare beneficiaries. CCW contains 17 years’ worth of data and includes enrollment/eligibility, assessment data, and fee-for-service institutional and noninstitutional claims. The U.S. Census Medicare beneficiary data (U.S. Census Bureau, 2015) are obtained from the March 2015 Current Population Survey Annual Social and Economic Supplement based on 2014 data.

Data for the percentage of individuals identifying as religious in 2014 were obtained from the Pew Research Center (Smith et al., 2015), whereas the measures for the 2014 per capita state income levels and 2010 education levels were accessed from the Bureau of Economic Analysis (2018) and the American Community Survey (U.S. Census Bureau, n.d.), respectively. Data on 2014 hospice by owner type and state-level racial/ethnicity measures were obtained from Hospice Analytics (2018) and the Kaiser Family Foundation (n.d.), respectively. The authors used Taylor et al.’s (2018) estimated cost savings per hospice enrollee based on the updated 2016 Medicare hospice payment structure. Taylor et al.’s study derived its findings from 2009 to 2010 Medicare claims data from North Carolina Medicare beneficiaries (N = 36,035).

**Measures**

The independent variable of for-profit hospice prevalence was calculated by the total amount of for-profit hospices per 10,000 Medicare beneficiaries for each state. The same calculation was used for nonprofit hospice prevalence for each state. Medicare beneficiaries include Medicare Advantage and fee-for-service beneficiaries. The percentage of individuals identifying as religious, the percentage of adults with at least a high school education, per capita income, and the percentage of racial/ethnic minorities within a state were included as covariates in the statistical model to control for state-level socioeconomic factors. The racial/ethnic minority hospice utilization disparity measure was calculated by dividing the percentage of racial/ethnic minorities using hospice by the percentage of racial/ethnic minorities enrolled in Medicare for each state. States were assigned a “1” if they possessed less of a disparity between racial/ethnic minority hospice Medicare patients and overall racial/ethnic minority Medicare enrollees compared with the median of all states (states with a value above 0.70) and a “0” otherwise.

For the projected cost savings from closing the gap between White and racial/ethnic minority Medicare hospice utilization, the breakdown by ethnicity followed the Kaiser Family Foundation Medicare beneficiary categories of Black, White, Hispanic, and Other. The Other category included Asians, Native Hawaiians and Pacific Islanders, American Indians, Aleutians, Eskimos, and
people of two or more races (Kaiser Family Foundation, 2017). To calculate the Medicare hospice participation rate by ethnicity, Medicare hospice beneficiaries within each racial group (CCW, 2018) were divided by the total number of Medicare beneficiaries within the same year (Kaiser Family Foundation, 2017). Then, the number of additional hospice enrollees necessary to match the higher White hospice utilization rate was calculated. Next, the projected mean cost savings of $2,105 per hospice enrollee (Taylor et al., 2018) was applied to estimate the potential cost savings from closing the racial/ethnic minority hospice utilization gap.

Analysis

Multivariate logistic regression was performed with the dependent variable being a dichotomous measure of whether or not a state had a relatively large racial/ethnic minority hospice usage gap. The independent variables of the study included the prevalence of for-profit and nonprofit hospices within a state as well as state-level socioeconomic measures of religiosity, racial/ethnic diversity, income, and education. All 50 U.S. states and Washington, D.C., were included in the analysis. StataSE version 15 (StataCorp LP, College Station, TX, USA) was utilized for statistical analyses.

Results

State Variable Summary Statistics

Table 1 displays the descriptive statistics of the study independent variables across the 50 states plus Washington, D.C. States tended to have more nonprofit hospices (0.65 per 10,000 state Medicare beneficiaries) versus for-profit hospices (0.59 per 10,000 state Medicare beneficiaries). In 2014, states on average had per capita incomes of $45,650 with 77% of the population stating they are religious, and 31% of the population representing non-White racial/ethnic categories as defined by the Kaiser Family Foundation (n.d.). In addition, 87% of the population earned a high school education or higher. The hospice utilization disparity was the dependent variable of focus. Nineteen states were assigned a “1” indicating that their minority hospice utilization disparity was below the national median.

Statistical Results.

Based on the logistic regression analysis displayed in Table 2, the prevalence of for-profit hospices was positively associated with racial/ethnic minority Medicare beneficiary hospice utilization, $\chi^2 (6, N = 51) = 17.76, p = .007.$ As the prevalence of for-profit hospices per Medicare beneficiary increases within a state, the probability increases that a state would have a lower than average hospice utilization gap between racial/ethnic minorities and the White population. No other coefficients were found to be significant.

The economic analysis found if racial/ethnic minority Medicare hospice utilization were to equal that of the current White Medicare hospice utilization, it would result in an estimated savings of nearly $270 million per year (Table 3).

Discussion

This study indicates a positive association exists between racial/ethnic minority Medicare hospice utilization and the prevalence of for-profit hospices. An estimated nationally representative annual savings of nearly $270 million in projected annual savings would result from closing the Medicare hospice utilization gap between racial/ethnic minorities and White Medicare beneficiaries.

The finding of the positive relationship between the prevalence of for-profit hospices and racial/ethnic minority Medicare utilization is not surprising given previous research showed for-profit hospices engage in greater community outreach to racial/ethnic minorities and low-income communities than nonprofit hospices.
addressing racial disparities in hospice utilization may contribute to the economic savings discussed in this article, particularly in increasing hospice enrollment among groups across socioeconomic levels is to include offering short bouts of increased emotional and physical support for the patient and/or caregiver(s) during times of crisis in end-of-life care (Barclay et al., 2013). Prior research suggested that both lower income and lower education were associated with lower rates of hospice care enrollment and at-home hospice death when holding other covariates constant (Barclay, Kuchibhatla, Tulsky, & Johnson, 2013; Jenkins et al., 2011; Silveira, Connor, Goold, McMahon, & Feudtner, 2011). The current study did not find significant relationships between state-level education and income measures and the minority hospice utilization gap. That said, the correlations in the individual-level studies between lower socioeconomic status and lower hospice utilization are not surprising given the significant role social determinants of health plays in end-of-life care decisions (Koroukian et al., 2017). A potential strategy for increasing hospice enrollment among groups across socioeconomic levels is to include offering short bouts of increased emotional and physical support for the patient and/or caregiver(s) during times of crisis in end-of-life care (Barclay et al., 2013). In addition, given informational materials hospices provide are not written at a level understood by most Americans (Kehl & McCarty, 2012), hospices should also focus on developing materials that comply with the Clear Communication initiative established by the National Institutes of Health. Clear Communication involves incorporating plain language and new technologies with accessible formats and content, all grounded in cultural respect (National Institutes of Health, n.d., para. 1).

Although policies targeting increased hospice enrollment levels for low-income populations with no specific focus on racial/ethnic minority populations would contribute to the economic savings discussed in this article, prior research has indicated that they would not eliminate the racial disparities within hospice enrollment. Brown et al. (2018) showed the effects of race/ethnicity on the intensity of end-of-life care are only partly mediated by other social determinants of health. Another study showed removing racial and ethnic disparities is complex and sometimes well-intended reform initiatives might inadvertently reinforce race/ethnic disparities (Alegria, Alvarez, Ishikawa, DiMarzio, & McPeek, 2016). Strategies hospices could use for specifically addressing racial disparities in hospice utilization may include offering materials in languages spoken by the targeted racial/ethnic minorities (Kehl & McCarty, 2012; Young, 2014) and employing bilingual and bicultural clinicians or trained staff who act as interpreters and provide cultural context for the clients’ beliefs and behaviors (Jackson & Gracia, 2014; Substance Abuse and Mental Health Services Administration, 2016).

This study estimated a projected savings of around $270 million annually from increasing the Medicare racial/ethnic minority hospice use rate to that of the White population. Several studies have estimated the higher end-of-life expenditures among racial/ethnic minority groups (Baicker et al., 2004; Byhoff et al., 2016; Hanchate et al., 2009; Kelley et al., 2011) and savings from hospice utilization, in general (Kelley et al., 2013; Taylor et al., 2018; Taylor, Ostermann, Van Houtven, Tulsky, & Steinhauser, 2007). However, to the authors’ knowledge, no other study has estimated the cost savings that could result from closing the hospice utilization gap. In addition to achieving cost savings, increasing Medicare racial/ethnic minority hospice use could potentially improve patient quality of care (Meier, 2011). As Livne (2014) states, “Limiting spending means helping people face their imminent death and avoiding prolonged aggressive treatment; in the context of hospice, it becomes a way of caring” (p. 906). For terminally ill Medicare patients, hospice often provides a lower cost care option emphasizing quality of life that meets patients’ preconceived wishes for end-of-life care (e.g., dying at home and being comfortable/without pain) (Kelley et al., 2013; Taylor et al., 2018; Teno et al., 2004; Wright et al., 2010; Zuckerman, Stearns, & Sheingold, 2016). Why racial/ethnic minority populations utilize this option less is subject to much discussion and debate (Elliott, Alexander, Mescher, Mohan, & Barnato, 2016; Pan et al., 2015). A systematic review of hospice use of Black people cited multiple factors contributing to relatively lower hospice utilization levels, including lack of hospice awareness, monetary concerns, mistrust of the health care system, a conflict in value with hospice care, and expected lack of racial/ethnic minority staff within hospice care (Washington, Bickel-Swenson, & Stephens, 2008). Alternately, Koss and Baker (2017) reported findings that question the common assertion that mistrust of the

| Table 3. Estimated Cost Savings From Closing Medicare Hospice Utilization Gap. |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                                | White           | Black           | Hispanic        | Other           | Total           |
| Medicare beneficiaries         | 38,505,300      | 5,160,600       | 4,137,400       | 2,742,900       | 50,546,200     |
| Hospice beneficiaries          | 1,112,625       | 107,461         | 68,776          | 43,499          | 1,332,361      |
| Hospice beneficiaries/Medicare | 2.89%           | 2.08%           | 1.66%           | 1.59%           | 2.64%          |
| Estimated cost savings from    | $87,686,851     | $106,882,881    | $75,270,839     | $269,840,571    |

aOther includes Asians, Native Hawaiians and Pacific Islanders, American Indians, Aleutians, Eskimos, and people of two or more races.

bSource: Kaiser Family Foundation (2017).

cSource: Chronic Conditions Data Warehouse (CCW; 2018).

dSource: Utilizes Taylor et al.’s (2018) cost savings estimate of $2,105 per beneficiary.
health system by Black older adults contributes to lower rates of advance care planning (a practice associated with receiving hospice care earlier and longer) (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Adams, Horn, and Bader (2007) emphasized the lack of access to health services prior to hospice admission for the U.S. Hispanic population as a significant reason for lower hospice use by that group.

Simply closing the gap on hospice enrollment will not eliminate racial disparities observed within hospice care. Research finds once in hospice care, Black people experience higher levels of disenrollment, often to pursue costly, more invasive end-of-life treatment (Aldridge, Canavan, Cherlin, & Bradley, 2015; Johnson, Kuchibhatla, & Tulsky, 2008). Research in this area is ongoing with one study finding, on average, Black and Hispanic people tended to enroll in hospices that provided a lower quality of care. However, within a particular hospice, Black and Hispanic people receive care that is similar to that of White people (Price, Parast, Haas, Teno, & Elliott, 2017). In contrast, another study found disparities existed between the quality of care for Black and White people within the same hospice setting (Rizzuto & Aldridge, 2018). Barclay et al. (2013) found Black people enrolled in hospice were also less likely to die at home compared with White people even when accounting for other socioeconomic factors such as income, location, and education. The explanation for the lower rate of at-home deaths for Black hospice patients is inconclusive, with some studies suggesting potential differences in culture, caretaker support, and hospice care communication may be contributors (Barclay et al., 2013).

This article discusses potential advantages (e.g., quality of life, lesser symptoms, and cost savings) from closing the current gap between racial/ethnic minority and White Medicare hospice utilization (Institute of Medicine, 1997; Kelley et al., 2013; Steinhauer et al., 2000). Recent research based on national survey data shows the disparities in health care access between Black and Hispanic people and White people have significantly narrowed from 2013 to 2015 after the passage of the Affordable Care Act (ACA). In addition to reducing racial and ethnic disparities, the ACA was associated with increased access for all three groups examined—Black, Hispanic, and White people, partly through Medicaid expansion (Hayes, Riley, Radley, & McCarthy, 2017). The racial and ethnic disparity within hospice is slightly different given that all citizens over 65 years of age, at least in theory, have access to hospice via their automatic Medicare enrollment. The disparities seen in hospice go beyond insurance accessibility or income (Harris et al., 2017; Ornstein et al., 2016). The hospice community outreach efforts discussed above (e.g., access improvements, materials at a lower reading level) would likely improve participation among people of all racial and ethnic backgrounds, including White people. Such increased enrollment across all racial and ethnic Medicare groups has the potential for even greater improvements in health and cost outcomes than addressed in this analysis.

This research has some limitations. First, due to a lack of variation estimates in the existing literature, it was assumed a similar proportion of Medicare beneficiaries would be eligible for hospice care across all racial groups. There is also the possibility the racial/ethnic minority Medicare beneficiaries, who would comprise the additional hospice enrollees, would have a different average length of stay, disease prevalence estimates, and disenrollment rates. The authors chose not to project these statistics because of the uncertainty as to the types of patients (e.g., diagnoses) greater hospice community outreach to racial/ethnic minorities would most attract. Second, this research is limited to state-level data. Future research is recommended examining the relationship between racial/ethnic minority Medicare hospice utilization and the prevalence of for-profit hospices that include additional variables of hospice users such as metropolitan status (e.g., rural vs. urban), gender, and income.

Another limitation is for-profit hospices have been shown to have higher levels of dementia patients compared with nonprofit hospices (Wachtman, Marcantonio, Davis, & McCarthy, 2011). Studies suggest dementia hospice patients have higher costs compared with nonhospice counterparts on account of relatively longer hospice stays and fewer invasive end-of-life treatments for this type of disease regardless of a patient’s hospice status (Taylor et al., 2018; Zuckerman et al., 2016). Another risk is enrolling patients in hospice too early, increasing chances of live discharge which research has shown is positively associated with both hospice profit margins and the proportion of patients from racial/ethnic minority groups (Dolin et al., 2017; Stevenson et al., 2016). If for-profit hospices improve racial/ethnic minority hospice enrollment by focusing solely on dementia patients and/or engage in too early enrollment practices—both of which are practices more associated with for-profit hospices than nonprofit hospices (Dolin et al., 2017; Stevenson et al., 2016)—and nonprofit hospices do not improve their racial/ethnic minority recruitment efforts across all primary diagnosis levels, the estimated cost savings discussed in this article could be overstated. Policymakers should be aware of this potential issue and ensure racial/ethnic minority hospice recruitment programs encourage hospice use across all eligible diseases. In addition, mechanisms should be in place to monitor both for-profit and nonprofit hospices to ensure quality of care remains paramount in decisions about recruiting and care.

**Conclusion**

With average per capita end-of-life medical spending in the last year of life at $80,000 in the United
States—comprising a larger fraction of its gross domestic product than that for all eight other countries examined in a 2017 study (French et al., 2017), implementing strategies to increase the inclusiveness of all racial/ethnic groups to hospice may be one way Medicare can simultaneously lessen its financial burden and improve the quality of life for its beneficiaries. This research finds a positive association between the prevalence of for-profit hospices and racial/ethnic minority Medicare hospice utilization, highlighting a potential business ownership model to further examine when developing strategies for racial/ethnic minority Medicare enrollees’ inclusion in hospice care. With the potential to provide nearly $270 million in annual cost savings while also improving health outcomes, further research on specific programs that successfully reduce the racial/ethnic minority hospice enrollment gap is paramount. In addition, collaboration between hospices, health systems, and community organizations is needed to reduce the disparities between racial/ethnic minority and White Medicare beneficiary hospice utilization.

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References
Adams, C. E., Horn, K., & Bader, J. (2007). Hispanics’ experiences in the health system prior to hospice admission. Journal of Cultural Diversity, 14(4), 155-163.
Alridge, M. D., Canavan, M., Cherlin, E., & Bradley, E. H. (2015). Has hospice use changed? 2000-2010 utilization patterns. Medical Care, 53, 95-101. doi:10.1097/ mlr.0000000000000256
Alridge, M. D., Schlesinger, M., Barry, C. L., Morrison, R. S., McCorkle, R., Hurzeler, R., & Bradley, E. H. (2014). National hospice survey results: For-profit status, community engagement, and service. JAMA Internal Medicine, 174, 500-506. doi:10.1001/jamainternmed.2014.3
Alegria, M., Alvarez, K., Ishikawa, R. Z., DiMarzio, K., & MePeck, S. (2016). Removing obstacles to eliminating racial and ethnic disparities in behavioral health care. Health Affairs, 35, 991-999. doi:10.1377/hlthaff.2016.0029
American Hospice Foundation. (n.d.). FAQ: Why do people choose to receive hospice care? Retrieved from https://americanhospice.org/learning-about-hospice/why-do-people-choose-to-receive-hospice-care/
Baicker, K., Chandra, A., Skinner, J. S., & Wennberg, J. E. (2004). Who you are and where you live: How race and geography affect the treatment of Medicare beneficiaries: There is no simple story that explains the regional pattern of racial disparities in health care. Health Affairs, 23(Suppl. 2), VAR33. doi:10.1377/hlthaff.var.33
Barclay, J. S., Kuchibhatla, M., Tulsy, J. A., & Johnson, K. S. (2013). Association of hospice patients’ income and care level with place of death. JAMA Internal Medicine, 173, 450-456. doi:10.1001/jamainternmed.2013.2773
Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. Journal of the American Geriatrics Society, 61, 209-214. doi:10.1111/jgs.12105
Brown, C. E., Engelberg, R. A., Sharma, R., Downey, L., Fausto, J. A., Sibley, J. . . . Curtis, J. R. (2018). Race/ethnicity, socioeconomic status, and healthcare intensity at the end of life. Journal of Palliative Medicine, 21, 1308-1316. doi:10.1089/jpm.2018.0011
Bureau of Economic Analysis. (2018). Personal income by state. Retrieved from https://www.bea.gov/data/income-saving/personal-income-by-state
Byhoff, E., Harris, J. A., Langa, K. M., & Iwashyna, T. J. (2016). Racial and ethnic differences in end-of-life Medicare expenditures. Journal of the American Geriatrics Society, 64, 1789-1797. doi:10.1111/jgs.14263
Chronic Conditions Data Warehouse. (2018). Medicare data. Retrieved from http://ccwdata.org
Dolin, R., Holmes, G. M., Stearns, S. C., Kirk, D. A., Hanson, L. C., Taylor, D. H., Jr., & Silberman, P. (2017). A positive association between hospice profit margin and the rate at which patients are discharged before death. Health Affairs, 36, 1291-1298.
Elliott, A. M., Alexander, S. C., Mescher, C. A., Mohan, D., & Barnato, A. E. (2016). Differences in physicians’ verbal and nonverbal communication with black and white patients at the end of life. Journal of Pain Symptom Management, 51(1), 1-8. doi:10.1016/j.jpainsymman.2015.07.008
French, E. B., McCauley, J., Aragon, M., Baxk, P., Chalkley, M., Chen, S. H., . . . Kelly, E. (2017). End-of-life medical spending in last twelve months of life is lower than previously reported. Health Affairs, 36, 1211-1217. doi:10.1377/hlthaff.2017.0174
Haines, K. L., Jung, H. S., Zens, T., Turner, S., Warner-Hillard, C., & Agarwal, S. (2018). Barriers to hospice care in trauma patients: The disparities in end-of-life care. American Journal of Hospice & Palliative Care, 35, 1081-1084. doi:10.1177/1049909117753377
Hanchate, A., Kronman, A. C., Young-Xu, Y., Ash, A. S., & Emanuel, E. (2009). Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? Archives of Internal Medicine, 169, 493-501. doi:10.1001/archinte.2008.616
Hardy, D., Chan, W., Liu, C. C., Cormier, J. N., Xia, R., Bruera, E., & Du, X. L. (2011). Racial disparities in the use of hospice services according to geographic residence and socioeconomic status in an elderly cohort with nonsmall cell lung cancer. Cancer, 117, 1506-1515. doi:10.1002/cncr.25669
Harris, J. A., Byhoff, E., Perumalswami, C. R., Langa, K. M., Wright, A. A., & Griggs, J. J. (2017). The relationship of obesity to hospice use and expenditures: A cohort study. *Annals of Internal Medicine, 166*, 381-389. doi:10.7326/m16-0749

Hayes, S. L., Riley, P., Radley, D. C., & McCarthy, D. (2017). Reducing racial and ethnic disparities in access to care: Has the Affordable Care Act made a difference? The Commonwealth Fund. Retrieved from https://www.commonwealthfund.org/publications/issue-briefs/2017/aug/reducing-racial-and-ethnic-disparities-access-care-has

Hospice Analytics. (2018). *National Hospice Locator*. Retrieved from http://www.nationalhospicanalytics.com/

Institute of Medicine. (1997). *Approaching death: Improving care at the end of life*. Retrieved from https://www.nap.edu/catalog/5801/approaching-death-improving-care-at-the-end-of-life

Jackson, C. S., & Gracia, J. N. (2014). Addressing health and health-care disparities: The role of a diverse workforce and the social determinants of health. *Public Health Reports, 129*(Suppl. 2), 57-61. doi:10.1177/00333549141291s21

Jenkins, T. M., Chapman, K. L., Ritchie, C. S., Arnott, D. K., McGwin, G., Cofield, S. S., & Maetz, H. M. (2011). Hospice use in Alabama, 2002-2005. *Journal of Pain and Symptom Management, 41*, 374-382. doi:10.1016/j.jpainsymmm.2010.04.027

Johnson, K. S., Kuchibhatla, M., & Tulsy, J. A. (2008). What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatrics Society, 56*, 1953-1958. doi:10.1111/j.1532-5419.2008.01919.x

Kaiser Family Foundation. (2017). *Distribution of Medicare payments in the last year of life*. Retrieved from https://www.kff.org/medicare/state-indicator/mc-pmts-in-the-last-year-of-life/

Keller, A. S., & McCarty, K. N. (2012). Readability of hospice materials to prepare families for caregiving at the time of death. *Research in Nursing & Health, 35*, 242-249. doi:10.1002/nur.21477

Kelley, A. S., Deb, P., Du, Q., Aldridge Carlson, M. D., & Morrison, R. S. (2013). Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay. *Health Affairs, 32*, 552-561. doi:10.1377/hlthaff.2012.0851

Kelley, A. S., Ettner, S. L., Morrison, R. S., Du, Q., Wenger, N. S., & Sarkisian, C. A. (2011). Determinants of medical expenditures in the last 6 months of life. *Annals of Internal Medicine, 154*, 235-242. doi:10.7326/0003-4819-154-4-201102150-00004

Koroukian, S. M., Schiltz, N. K., Warner, D. F., Given, C. W., Schluchter, M., Owusu, C., & Berger, N. A. (2017). Social determinants, multimorbidity, and patterns of end-of-life care in older adults dying from cancer. *Journal of Geriatric Oncology, 8*, 117-124. doi:10.1016/j.jgo.2016.10.001

Koss, C. S., & Baker, T. A. (2017). A question of trust: Does mistrust or perceived discrimination account for race disparities in advance directive completion? *Innovation in Aging, 1*(1), igx017. doi:10.1093/geroni/igx017

Lrnie, R. (2014). Economies of dying: The moralization of economic scarcity in U.S. hospice care. *American Sociological Review, 79*, 888-911. doi:10.1177/0003122414547756

Martin, M. Y., Psu, M., Oster, R. A., Urmie, J. M., Schrag, D., Huskamp, H. A., . . . Fouda, M. N. (2011). Racial variation in willingness to trade financial resources for life-prolonging cancer treatment. *Cancer, 117*, 3476-3484. doi:10.1002/cncr.25839

Meier, D. E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly, 89*, 343-380. doi:10.1111/j.1468-0011.2011.01063.x

National Hospice and Palliative Care Organization. (2018). *NHPCO facts and figures: Hospice care in America*. Alexandria, VA: Author.

National Institutes of Health. (n.d.). *Clear communication*. Retrieved from https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liason/clear-communication

Ornstein, K. A., Aldridge, M. D., Mair, C. A., Gorges, R., Siu, A. L., & Kelley, A. S. (2016). Spousal characteristics and older adults’ hospice use: Understanding disparities in end-of-life care. *Journal of Palliative Medicine, 19*, 509-515. doi:10.1089/jpm.2015.0399

Pan, C. X., Abraham, O., Giron, F., LeMarie, P., & Pollack, S. (2015). Just ask: Hospice familiarity in Asian and Hispanic adults. *Journal of Pain and Symptom Management, 49*, 928-933. doi:10.1016/j.jpainsymmm.2014.09.016

Price, R. A., Parast, L., Haas, A., Teno, J. M., & Elliott, M. N. (2017). Black and Hispanic patients receive hospice care similar to that of white patients when in the same hospices. *Health Affairs, 36*, 1283-1290. doi:10.1377/hlthaff.2017.0151

Ramey, S. J., & Chin, S. H. (2012). Disparity in hospice utilization by African American patients with cancer. *American Journal of Hospice & Palliative Care, 29*, 346-354. doi:10.1177/1049909111423804

Riley, G. F., & Lubitz, J. D. (2010). Long-term trends in Medicare payments in the last year of life. *Health Services Research, 45*, 565-576. doi:10.1111/j.1475-773X.2010.01082.x

Rizzuto, J., & Aldridge, M. D. (2018). Racial disparities in hospice outcomes: A race or hospice-level effect? *Journal of the American Geriatrics Society, 66*, 407-413. doi:10.1111/jgs.15228

Silveira, M. J., Connor, S. R., Goold, S. D., McMahon, L. F., & Feudtner, C. (2011). Community supply of hospice: Does wealth play a role? *Journal of Pain and Symptom Management, 42*, 76-82. doi:10.1016/j.jpainsymmsym.2010.09.016

Smith, G., Cooperman, A., Mohamed, B., Martinez, J., Alper, B., Sciuipac, E., & Gecewicz, C. (2015). *America’s changing religious landscape: Christians decline sharply as share of population; unaffiliated and other faiths continue to grow*. Washington, DC: Pew Research Center.

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsy, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine, 132*, 825-832.

Stevenson, D. G., Grabowski, D. C., Keating, N. L., & Huskamp, H. A. (2016). Effect of ownership on
Substance Abuse and Mental Health Services Administration. (2016). *Improving cultural competence*. Retrieved from https://store.samhsa.gov/system/files/sma16-4932.pdf

Taylor, D. H., Jr., Bhavasar, N. A., Bull, J. H., Kassner, C. T., Olson, A., & Boucher, N. A. (2018). Will changes to Medicare payment rates alter hospice’s cost-saving ability? *Journal of Palliative Medicine*, 21, 645-651. doi:10.1089/jpm.2017.0485

Taylor, D. H., Jr., Ostermann, J., Van Houtven, C. H., Tulsky, J. A., & Steinhauser, K. (2007). What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? *Social Science & Medicine*, 65, 1466-1478. doi:10.1016/j.socscimed.2007.05.028

Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *The Journal of the American Medical Association*, 291, 88-93. doi:10.1001/jama.291.1.88

Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wettle, T. (2007). Association between advance directives and quality of end-of-life care: A national study. *Journal of the American Geriatrics Society*, 55, 189-194. doi:10.1111/j.1532-5415.2007.01045.x

U.S. Census Bureau. (2015). *Current Population Survey Annual Social and Economic Supplement (CPS-ASEC)*. Retrieved from https://www.census.gov/topics/health/health-insurance/guidance/cps-asec.html

U.S. Census Bureau. (n.d.). *American Community Survey*. Retrieved from https://www.census.gov/programs-surveys/acs

Wachterman, M. W., Marcantonio, E. R., Davis, R. B., & McCarthy, E. P. (2011). Association of hospice agency profit status with patient diagnosis, location of care, and length of stay. *The Journal of the American Medical Association*, 305, 472-479. doi:10.1001/ jama.2011.70

Washington, K. T., Bickel-Swenson, D., & Stephens, N. (2008). Barriers to hospice use among African Americans: A systematic review. *Health & Social Work*, 33, 267-274.

Wright, A. A., Keating, N. L., Balboni, T. A., Matulonis, U. A., Block, S. D., & Prigerson, H. G. (2010). Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers’ mental health. *Journal of Clinical Oncology*, 28, 4457-4464. doi:10.1200/jco.2009.26.3863

Young, J. S. (2014). Online resources for culturally and linguistically appropriate services in home healthcare and hospice: Resources for Spanish-speaking patients. *Home Healthcare Nurse*, 32(5, Suppl.), S12-S18. doi:10.1097/nhh.0000000000000081

Zuckerman, R. B., Stearns, S. C., & Sheingold, S. H. (2016). Hospice use, hospitalization, and Medicare spending at the end of life. *Journal of Gerontology, Series B: Psychological Sciences & Social Sciences*, 71, 569-580. doi:10.1093/geront/gbv109