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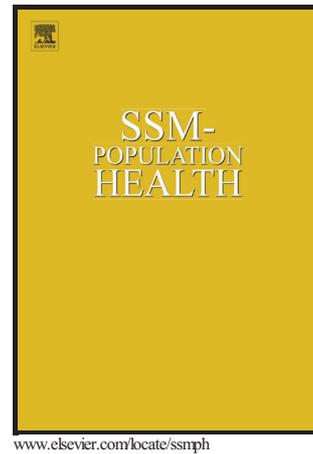
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Racial and ethnic differences in end-of-life care in the United States: Evidence from the

Health and Retirement Study (HRS)

Martina Orlovic[a], Katharine Smith[b], Elias Mossialos[c]

[a]Department of Surgery and Cancer, Faculty of Medicine, Institute of Global Health Innovation,10th Floor, QEQM Wing, St Mary's Hospital, South Wharf Road, London, W2 1NY, United Kingdom
[b]Centre for Health Policy, Institute of Global Health Innovation, Imperial College London, 10th Floor, QEQM Wing, St Mary's Hospital, South Wharf Road, London, W2 1NY, United Kingdom

[c]Department of Surgery and Cancer, Faculty of Medicine, Institute of Global Health Innovation, 10th Floor, QEQM Wing, St Mary's Hospital, South Wharf Road, London, W2 1NY, United Kingdom

[d]Professor of Health Policy and Head of Department in the Department of Health Policy, London School of Economics and Political Science, Houghton St, London, WC2A 2AE, United Kingdom.

*Corresponding author: Martina Orlovic (corresponding author), 004407928962060. m.orlovic15@imperial.ac.uk

Abstract

Population ageing poses considerable challenges to the provision of quality end-of-life care. The population of the United States is increasingly diverse, making it imperative to design culturally sensitive end-of-life care interventions. We examined participants of the Health and Retirement Study, who died between 2002 and 2014, to examine racial and ethnic differences in end-of-life care utilization and end-of-life planning in the United States. Our study reveals significant disparities in end-of-life care and planning among studied groups. Findings reveal that racial and ethnic minorities are more likely to die in hospital and less likely to engage in end-of-life planning activities. The observed disparities are still significant but have been narrowing between 2002 and 2014. Efforts to reduce these differences should target both medical professionals and diverse

communities to ensure that improved models of care acknowledge heterogeneous values and needs of a culturally diverse US population.

Keywords: end-of-life, advance care planning, living will, Health and Retirement study

1. Introduction

On average, more than 2.5 million people die every year in the United States (US), a number that is set to increase due to recent population trends (Kochanek, Murphy, Xu, & Arias, 2017). Dying is inevitable, but care at the end-of-life is heterogeneous. End-of-life care includes not only pain and symptom management, but also provision of psychological, social, spiritual and practical support which may differ between cultural groups. There is a growing need for the US to meet the end-of-life care needs of an ethnically and racially diverse population. By 2050 there is estimated to be 33 million black American, Hispanic, Asian, American Indian or Alaskan Native individuals age 65 years and older. This represents nearly 40% of the population of this age group (Ortman & VelKoff, 2014). Culturally sensitive end-of-life care is one of the US national priorities, as identified by the National Consensus Project for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2018).

The delivery of end-of-life care is complex, involving public, private, and informal care providers. A successful health system supports the provision of patient-centered care: providing the right care at the right time and according to patient preferences (Wolf, Berlinger, & Jennings, 2015). Planning in advance for end-of-life care services is

essential to support patient-centered care. It allows patients to die with dignity, taking into account their needs as well as the needs of their families and carers, and working in the context of scarce healthcare resources.

Health care disparities are extensively documented for African American and Hispanic people compared to whites in the United States across a range of diseases (Walkey et al., 2017). For example, African American and Hispanic people tend to receive fewer medical services and have less healthcare spending than white individuals (Walkey et al., 2017). It has been suggested that this pattern may be reversed at the end-of-life (Hanchate, Kronman, Young-Xu, Ash, & Emanuel, 2009). Recently, growing body of literature offers population-level evidence on behaviors and care disparities among dying patients (Johnson, 2013). Research has demonstrated racial differences in aspects of end-of-life care, although the gap appears to be narrowing (Koss & Baker, 2017). Previous research has also found ethnic minorities to prefer more aggressive treatment at the end-of-life, compared to white people (Koss & Baker, 2017; Kwak & Haley, 2005). Research has differed in the causes they attribute to these differences. A number of studies found that cultural values, knowledge, and socio-economic status accounted for racial differences in possession of advance directives (Carr, 2012; Clark, Person, Gosline, Gawande, & Block, 2018; Loggers et al., 2009; Smith, Earle, & McCarthy, 2009). More recently, studies found that, even accounting for confounding factors like these, the effect of race on possession of advance directives persists (Huang, Neuhaus, & Chiong, 2016).

Although the research on racial and ethnic end-of-life disparities is growing, there are still significant content gaps and methodological limitations (Johnson, 2013). Largely,

the studies have been more focused on African Americans and less on Hispanics that form two largest minority groups in the US. Also, disparities in cancer patients have been studied more extensively, while there is less research focusing on other highly prevalent conditions such as cardiovascular or respiratory conditions. Further, many studies used convenience sample design which compromises generalizability of results. Finally, more research is needed on mediators of disparities among patients (Johnson, 2013). This paper makes a contribution to the literature by addressing the challenges of current body of literature and broadening the scope of previous research. It examines four hypotheses simultaneously, spanning health and retirement end-of-life care behaviors and practices in order to explain recent end-of-life trends in the general US population. Firstly, we hypothesize that African American and Hispanic people are more likely to die in hospital compared to white Americans. Secondly, we presume that non-white Americans are more likely to be exposed to more intensive treatments at the end-of-life compared to their white counterparts. This is likely due to a higher preference for life-prolonging treatments, lower medical literacy, lower uptake of newly developed end-of-life care policies, and unequal access to non-hospital end-of-life services (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009; Crawley et al., 2000). Thirdly, we expect that African American and Hispanic individuals are less likely to be engaged in planning activities for the end-of-life than white Americans. Finally, attitudes towards end-of-life planning can also be influenced by religious beliefs, which is strongly related to individuals' cultural heritage (Kagawa-Singer & Blackhall, 2001; Phelps et al., 2009). In our fourth hypothesis, we expect that religion is an important factor in relation to end-of-life planning, irrespective of race and ethnic origin.

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The study uses the Health and Retirement Study (HRS) – the largest longitudinal survey of a representative sample of Americans to examine nationwide cultural disparities in end-of-life care and planning. Even though the HRS has been used before, this is the first time it is used to provide an extensive insight into end-of-life care and planning, over more than a decade, and including not only clinical, but also individual characteristics, spanning from racial and ethnic origin to religiousness. Knowledge of disparities and social patterns of end-of-life care can support the design of policies to facilitate better access to end-of-life services across a diverse population and reduce existing differences.

2. Methods

2.1 Sample

Our analysis uses a sample of 9,228 participants of the HRS, pooled across 6 survey waves, from 2002 to 2014. These periods were included because questionnaires in these survey waves included data on the presence of the living will. HRS is a nationally representative, biennial, longitudinal panel survey of individuals of 50 years of age and older, designed to study health and retirement among older people in the US (D. Bugliari et al., 2016). HRS, initiated in 1992, is based on in-depth interviews of more than 37,000 individuals on four major components of their lives: health, work and retirement, social connections and economic status. The survey is a rich data source which provides an insight into aging trajectories in America.

This analysis is based on HRS exit interviews, a special type of interview conducted with a proxy-respondent after the participant's death. The proxy-respondent is identified

from the deceased's social network and is usually a close family member. The exit interview gives a detailed insight into the deceased's last year of life and death circumstances. Even though attrition is a common issue in longitudinal studies, that is minimized in the HRS due to frequent contact with study participants. Only 6.8% of study participants have dropped out due to attrition, while 36.8% have died since the beginning of the study (Fisher & Ryan, 2018). Exit interview is completed with almost all survey participants who died, ranging from 85.5% in 2002 to 97.9% in 2012 (D. Bugliari et al., 2016; Weir, 2016). Therefore, in the HRS mortality surveillance is considered complete (Weir, 2016).

2.2 Analyses

Analyses were performed using the statistical software STATA (Version 13). Multinomial logistic regression was employed to identify the impact of racial and ethnic background and patient characteristics on the place of death, a proxy for the intensity of end-of-life care. The outcome variable, place of death, had four possible categories: home, nursing home, hospice and hospital, the latter of which was a reference category. Explanatory variables included in the equation were racial and ethnic background (Non-Hispanic white, Non-Hispanic black, Hispanic white and other), age, gender, education level (lower than high school level, high school level, graduate level), income quintiles, cohabitation status, number of resident children, number of difficulties with activities of daily living (ADL), duration of terminal illness (less than a month, less than a year, more than a year), underlying cause of death (cancer, cardiovascular disease, allergies and pulmonary disease, disease of digestive system or other), number of health insurance plans, enrolment in Medicare fee-for-service (FFS) or Medicare health maintenance

organization (HMO), presence of written end-of-life instructions, census region (North-East, Midwest, South, East), and a set of wave dummy variables to control for time trends. Non-Hispanic black refers to African Americans and Hispanic white refers to Hispanic individuals.

Additional outcomes were examined using logistic regression to better describe the intensity of end-of-life care. Adjusting for the same explanatory variables, the following binary outcomes were examined: short stay in hospital (less than a week), use of life support, use of kidney dialysis and time spent in an intensive care unit (ICU). These outcomes are established indicators of overly intensive end-of-life care (Gidwani-Marszowski et al., 2018). All outcomes describe individuals' healthcare utilization in their final moments of life.

The presence of written end-of-life instructions was used as an indicator of end-of-life planning. The initial model specification included the same explanatory variables as in the multinomial model. The second model specification included additional variables to identify the role of religion: religious adherence (often, sometimes and never) and religious importance (very important and not very important). Finally, the third model specification looked for interactions between racial/ethnic background and religious importance to determine whether the influence of race/ethnicity is a function of the individual's religiousness.

3. Furthermore, to better describe individuals' end-of-life preferences and planning activities, the following outcomes were assessed using logistic regression: end-of-life instructions express a desire to receive all care possible, end-of-life instructions express a desire to have any treatment withheld, last decisions involved withholding

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treatment, respondent had an end-of-life legal care arrangement, and weather respondent ever discussed end-of-life care. Finally, for those individuals who had written end-of-life instructions, and when the timing of these was known, adjusted average time for end-of-life planning was examined using regression analysis. This provides insight into the time when individuals engage in end-of-life planning activities as well as the importance of doing so. As HRS oversamples African American and Hispanic populations, respondent-level sample weights were applied to account for the unequal probabilities of selection between core and oversampled population. These sample weights are non-zero values for living respondents born in the particular year (Health and Retirement Study, 2002). As the analysis is using exit interviews, respondent-level weights for the wave prior death are used to obtain appropriate non-zero values. These HRS respondent-level weights are post-stratified to national totals and designed on the basis of birth cohorts for both genders and for each ethnic and racial group in order to capture the major characteristics of the sample design (Health and Retirement Study, 2002). That way, applied weights provide consistent adjustment for sample attrition and mortality (Health and Retirement Study, 2002).

4. Results

4.1 Place of death and intensity of end-of-life care

Descriptive results reveal a higher proportion of Non-Hispanic blacks (43.5%) and Hispanic whites (43.4%) who die in hospital compared to Non-Hispanic whites (33.7%) (Exhibit 1). Further, Non-Hispanic white Americans are more likely to die in nursing home (26.6%) compared to Non-Hispanic black (18.3%) and Hispanic white (13.8%)

people. Although still existing, disparities in place of death have been narrowing between 2002 and 2014 (Appendix A). That is especially evident for deaths in hospice and hospital, while there is still significant and persisting difference in the proportion of deaths in nursing homes between white and non-white individuals. These findings were examined further using regression analyses.

Exhibit 1 [Figure]

A range of individual characteristics are associated with the place of death (Exhibit 2) Racial and ethnic differences persist even when adjusting for a range of individual confounders. Holding other variables constant, the odds of African Americans dying at home rather than in hospital are 23.2% lower compared to white Americans. Similarly, the same individuals are 35.5% less likely to die in a nursing home and 27.9% less likely to die in a hospice rather than in hospital, compared to their white counterparts. Further, Hispanics have 50.2% lower odds of dying in a nursing home rather than in hospital, compared to white Americans.

In addition to race and ethnicity, other individual characteristics also influence the site of death. Younger individuals, and those that suffer from short-term illnesses or experience an organ failure are more likely to die in hospital. In contrast, higher-income individuals, those who have in-house support or those who suffer from cancer are more likely to die outside of the hospital setting. Finally, individuals who have more insurance plans and are enrolled in a Medicare HMO plan are more likely to utilize non-hospital based end-of-life care, such as hospice or nursing home care. This is due to having a more comprehensive insurance package, different financial incentives and better affordability of out-of-hospital end-of-life care (Chen & Miller, 2017).

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Exhibit 2 [Table]

Additionally, a range of outcomes were assessed to better describe intensity of end-of-life care among individuals of diverse racial and ethnic background (Exhibit 3). African American and Hispanic people are more likely to be exposed to overly intensive care in the last moments of their life in terms of increased use of life support (OR(AA)=1.49; OR(H)=2.44) and use of kidney dialysis before death (OR(AA)=1.79; OR(H)=1.83) compared to white Americans. Also, African Americans are more likely to have a short stay (less than one week) in hospital before death (OR(AA)=1.44), compared to the white population. This could be due to differences in their reasons for being in hospital. The data show that white Americans are more likely to be admitted to hospital for surgery, while African Americans are more likely to be in hospital to relieve symptoms. The full statistical output is shown in Appendix B.

Exhibit 3 [Figure]

4.2   Planning for the end-of-life

Race/ethnicity is an important determinant of end-of-life planning (Exhibit 4). African Americans (OR(AA)=0.31) and Hispanics (OR(H)=0.32) are significantly less likely than white individuals to have a living will. These differences persist even when adjusting for religious adherence and importance which are important characteristics of an individual's culture associated with a lower likelihood of having written end-of-life instructions. Further, individuals who were engaged in discussions around end-of-life care are significantly more likely to have written end-of-life instructions. Also, females, older, more educated, wealthier individuals, and those that suffer from cancer are more

likely to plan for their end-of-life. Surprisingly, living with a partner or with children is associated with a lower likelihood of having written end-of-life instructions.

Exhibit 4 [Table]

Multivariable analysis of secondary outcomes for end-of-life planning revealed that African American and Hispanic individuals are less likely than white individuals to engage in any type of end-of-life planning activities (Exhibit 5). Additionally, even when they plan for their death, the instructions are written on average 19 months closer to their death compared to those of white Americans. This suggests that white Americans place a higher value on and prioritize end-of-life planning more than other racial and ethnic groups. African American (OR(AA)=0.50) and Hispanic individuals (OR(H)=0.49), compared to their white counterparts, are unlikely to discuss their end-of-life care before death. Also, they are unlikely to have any legal arrangements regarding their care (OR(AA)=0.36; OR(H)=0.35) and it is unlikely that their decisions will involve withholding any treatment (OR(AA)=0.46; OR(H)=0.52). Non-white Americans express a strong preference to receive all care possible (OR(AA)=2.25; OR(H)=5.50) and to not have any treatment withheld (OR(AA)=0.37; OR(H)=0.52). Additional regression output is shown in Appendix C.

Exhibit 5 [Figure]

5. Discussion

This paper provides a comprehensive and up-to-date overview of end-of-life circumstances and planning for a representative sample of ethnically and racially diverse Americans. To the best of authors' knowledge, this is the first study that provides insight into determinants of the place of death, availability and the content of

advance directives using 12 years of nationally representative data and examining simultaneously impact of various individual characteristics, ranging from racial and ethnic background to religiousness. People from minority groups in the US are more likely to die in a hospital setting and have more intensive treatments at the end-of-life compared to white Americans, which confirms our first and second hypothesis (Crawley et al., 2000; Institue of Medicine, 2015; Iwashyna & Chang, 1993). The differences persist even when accounting for the usual confounders. Previous research has suggested that higher rates of acute end-of-life care among minorities could exist for a variety of reasons spanning the social and the personal (Barnato et al., 2009; Kagawa-Singer & Blackhall, 2001). Certainly, racial and ethnic differences in the possession of resources go beyond income and education (Iwashyna & Chang, 1993). For example, African Americans and Hispanics generally live in larger households and are considered to have stronger social networks, which provides the opportunity to facilitate in-house death (Iwashyna & Chang, 1993). Further, Hispanic and African American families often rely on collective decision-making and family-oriented care, which could play a part in reducing a reliance on hospices and other long-term care services (Kagawa-Singer & Blackhall, 2001). Despite this, most minorities still die in a hospital setting and utilize overly intensive end-of-life care.

Long-term care availability, in terms of hospice and nursing homes, differs between rural and urban areas and lower utilization of such services has been documented for minorities compared to predominately white areas (Givens, Tjia, Zhou, Emanuel, & Ash, 2010; Loggers et al., 2013). This indicates unequitable access to these services for minority populations and may contribute to higher use of acute end-of-life services in

minority populations, since their choice of different types of end-of-life services is restricted. In addition, minorities are less likely to be informed about different care options at the end-of-life (Givens et al., 2010). Less informed individuals, especially those enrolled in FFS Medicare plans, may be more prone to the influence from medical professionals and supplier-induced demand (Chen & Miller, 2017). This may partly explain more intensive care at the end-of-life in minorities. Even though the differences exist, they appear to be narrowing due to public- and private- sector efforts in promoting the use of palliative care services and supporting related professional education and public engagement (Institue of Medicine, 2015; Koss & Baker, 2017). The number of Medicare beneficiaries enrolled into Medicare Hospice Benefit, a public insurance program intended for the last few months of beneficiary's life, more than doubled between 2000 and 2011, from 0.5 million to more than 1.2 million (Institue of Medicine, 2015). Further, studies have demonstrated cultural differences towards life-prolonging technology, attitudes and preferences for different end-of-life treatments and decision-making at the end-of-life (Kagawa-Singer & Blackhall, 2001). African Americans and Hispanics express a strong preference for intensive end-of-life care (Crawley et al., 2000). Even if intensive end-of-life care is a cultural choice, this may stem from mistrust in the healthcare system, perceived lower quality of care and unequitable access to necessary services throughout their lives (Crawley et al., 2000; Hanchate et al., 2009; Kagawa-Singer & Blackhall, 2001). According to the Agency for Healthcare Research and Quality (AHRQ), African Americans and Hispanics receive less preventive care, lower quality care and worse access to care (Agency for Healthcare Research and Quality, 2016). Consideration of different end-of-life care choices is facilitated by regular

interactions with healthcare professionals; those without established care providers are unlikely to be aware of these choices.

Advance care planning is widely recognized as a beneficial mechanism for patients to maintain autonomy over their end-of-life care decisions because it allows patient preferences to be considered at a future date when patients are unable to express them (Institue of Medicine, 2015; Silveira, Kim, & Langa, 2010). It can take a number of forms including the living will and durable power of attorney. The HRS provides the opportunity to gain insights into advance care planning patterns of Americans, as it contains information on the availability and content of the living wills. Our findings indicate that African American and Hispanic individuals are less likely to engage in advance care planning, which confirms our third hypothesis. This is consistent with previous research that found that minority groups are less likely to have an advance directive or a healthcare proxy compared to white people (Huang et al., 2016; Institue of Medicine, 2015; Kagawa-Singer & Blackhall, 2001; McAfee, Jordan, Sheu, Dake, & Kopp Miller, 2017). Also, religion is an important determinant of end-of-life planning. More religious individuals are less likely to engage in end-of-life planning activities, a finding that confirms our fourth hypothesis. Religious individuals may describe pain and suffering as something that must be endured, not avoided and that only God has the power to make decisions about ending life (Fang, Sixsmith, Sinclair, & Horst, 2016; Kagawa-Singer & Blackhall, 2001). Even though religion is an important factor in end-of-life planning, differences in religion do not account for or explain the differences observed between racial/ethnic groups.

Previous research has highlighted reasons for these racial and ethnic disparities in engaging with advance care planning. Mistrust in healthcare professionals and the health system more generally, perhaps due to previous mistreatment, is a frequently expressed explanation (Institue of Medicine, 2015; Kagawa-Singer & Blackhall, 2001; McAfee et al., 2017). In fact, African Americans are more likely to believe they would be given poorer-quality medical treatment and be treated differently if they completed an advance care directive (Clark et al., 2018; Kagawa-Singer & Blackhall, 2001; McAfee et al., 2017). Also, it has been suggested that a lack of knowledge of advance care planning as well as lower health literacy are reasons for low completion of living wills among minorities (Bullock, 2006; Kermel-Schiffman & Werner, 2017). Another explanation could be that collective decision-making is more prevalent in cultures of observed minorities which could emphasize the role of family input into end-of-life care and be a reason for greater reluctance among minorities to have a living will (Clark et al., 2018). Further, having an end-of-life discussion substantially increases the likelihood of having a living will. In our dataset, however, among those who had a conversation about their end-of-life wishes, only 12% were African American and 6% were Hispanic. While this may reflect reluctance among minorities to engage in such activities, in addition there may be significant access barriers to these types of services. Since 2016, Medicare reimburses physicians for these conversations, which may reduce access barriers for minorities and improve completion rates of advance directives (Griffin et al., 2016). Preferences in terms of withholding treatment also differ along cultural lines. Compared to white Americans, minorities express a strong desire to receive all care possible and not to have any treatment withheld at the end of life. This further

strengthens perceived mistrust in the healthcare system. Language barriers and a lack of familiarity with the healthcare system can further deepen access barriers for minorities and discourage them from end-of-life planning (Burdsall, 2013).

5.1 Limitations

The analysis is based on data obtained from proxy-respondents which may be subject to response bias and loss of information. The HRS does not verify the accuracy of information against Medicare records (Chen & Miller, 2017). However, the majority of proxy-respondents (88%) are close family members, so are likely to be aware of the end-of-life circumstances of their loved ones. Also, although mortality ascertainment in the study is considered high-quality and complete (Weir, 2016), small proportion exit interviews could not be carried out which may undermine results representatives. Further, the HRS provides limited information about the intensity of end-of-life care, so more comprehensive analysis could not be conducted. Future research should include Medicare claims data to examine the type and intensity of care in more detail. The survey is not designed to assess quality of care and does not provide adequate information about it, so we were only able to observe racial and ethnic differences in types of end-of-life care received. Also, the survey does not provide data on the characteristics of individuals' living settings and we were unable to control for the availability of acute and long-term care services, which may impact healthcare utilization at the end-of-life (Orlovic, Carter, Marti, & Mossialos, 2017). Additionally, information on the level of health literacy, which may be important for discerning end-of-life preferences and recording end-of-life instructions, was unavailable (Smith et al., 2009). The HRS provides limited information on local and regional differences in available health care

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resources which may be important in explaining differences in end-of-life care utilization (Keating et al., 2018; Tschirhart, Du, & Kelley, 2014). Even though we control for a range of individual characteristics that may impact end-of-life circumstances, some important determinants of end-of-life care may remain unobserved. Finally, the study has cross-sectional design, which limits the ability to make causal inferences.

5.2 Policy implications

Advance care planning is an important part of the provision of patient-centered and cost-effective care (Boerner, Carr, & Moorman, 2013). An understanding of patient pathways at the end-of-life facilitates access to timely end-of-life care which can improve health outcomes, prevent over treatment and ensure cost-effective use of healthcare resources. National investments in long-term care infrastructure could increase access to alternative, out-of-hospital types of end-of-life care, enabling more comprehensive public support for terminally ill patients of all cultural groups (Mack, Weeks, Wright, Block, & Prigerson, 2010). Also, financial incentives and organizational arrangements should be designed in a way to prevent supplier-induced demand. That requires alternatives to FFS reimbursement such as development of accountable care organizations, bundled payments, or introducing penalties for high 30-day readmission rates, hospital mortality, and poor patient experience (Institue of Medicine, 2015). Expanding insurance coverage to include additional long-term care services is worthwhile because it could reduce the pressure on acute end-of-life services, but in the context of rising healthcare costs it will be challenging to secure public support for these services. Further, recorded end-of-life preferences are associated with better quality end-of-life care (Mack et al., 2010; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007).

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Policies should ensure equitable access to care throughout an individual's life, not only as it ends. Also, special attention should be given to familiarizing minorities with different treatment options at the end-of-life and with the benefits of advance care planning. This could be achieved with culturally-tailored community-based interventions. Further, clear communication from healthcare professionals, both to patients and to their families, is of crucial importance. In cases where preferences are based on well-informed decisions, these should be considered and approached in a culturally-sensitive way. This may require additional education of healthcare professionals, so they can be better equipped to work with culturally diverse populations. These actions could improve overall medical literacy of minorities, perceived care quality and satisfaction, and trust in the healthcare system.

6. Conclusion

This study provides an analysis of end-of-life circumstances of the American population. There are marked racial and ethnic disparities at the end-of-life, even when adjusting for a range of individual characteristics. The demand for culturally-sensitive end-of-life care will continue to rise due to a growing ethnically and racially diverse population of older adults. Efforts to reduce existing discrepancies should target both patients and healthcare professionals to ensure that new models of care accommodate the diverse needs of older adults. Securing these conditions for high-quality end-of-life care is likely to require dedicated support from governmental structures. The millions of Americans that deal with life-threatening conditions deserve access to adequate patient-centered end-of-life care.

Declaration of Interest statement: None.

Exhibit list

- EXHIBIT 1 (figure)

Caption: Place of death by race and ethnicity

Source: Authors' analysis of data from the Health and Retirement Study, 2002 - 2014

- EXHIBIT 2 (table)

Caption: Multinomial logistic regression analysis of determinants of place of death

Source: Source: Authors' analysis of data from the Health and Retirement Study, 2002 – 2014.

Notes: Presented results are from multinomial logistic regression analysis. Results are presented as relative risk ratios (RRR), indicating percentage relative risk change for a unit increase in the observed variable compared to the reference group, holding other variables constant. The base outcome is 'Dying in hospital'. *P<0.1, **P<0.05, ***P<0.001. For categorical variables, the reference category is stated in the row label, otherwise the reference is the complementary category.

- EXHIBIT 3 (figure)

Caption: Differences in intensity of end-of-life treatment by race and ethnicity

Source: Source: Authors' analysis of data from the Health and Retirement Study, 2002 – 2014.

Notes: The error bars indicate 95 percent confidence intervals. *P<0.1, **P<0.05, ***P<0.001.

- EXHIBIT 4 (table)

Caption: Logistic regression analysis of determinants of end-of-life planning

Source: Source: Authors' analysis of data from the Health and Retirement Study, 2002 – 2014.

Notes: Presented results are from univariate logistic regression analysis. Results are presented as odds ratios, indicating percentage odds change for a unit increase in the observed variable, holding other variables constant. *P<0.1, **P<0.05, ***P<0.001. For categorical variables, the reference category is stated in the row label, otherwise the reference is the complementary category.

- EXHIBIT 5 (figure)

Caption: Differences in end-of-life planning by race and ethnicity

Source: Source: Authors' analysis of data from the Health and Retirement Study, 2002 – 2014.

Notes: The error bars indicate 95 percent confidence intervals. *P<0.1, **P<0.05, ***P<0.001. R denotes the respondent.

Exhibit 2: Multinomial logistic regression analysis of determinants of place of death

Independent variable	Place of death (Sample=6471)					
	Home		Nursing Home		Hospice	
	RRR	P>|z|	RRR	P>|z|	RRR	P>|z|
Intercept	0.170	0.000***	0.004	0.002**	0.003	0.001**
Race/ethnicity (Ref: Non-Hispanic white)						
Non-Hispanic black	0.768	0.006**	0.645	0.000***	0.721	0.035**
Hispanic white	0.859	0.276	0.498	0.000***	0.913	0.689

	RRR	p	RRR	p	RRR	p
Other	0.717	0.152	0.460	0.026**	0.451	0.139
Age	1.004	0.238	1.060	0.000***	1.030	0.000***
Gender (Ref: Male)	1.017	0.813	1.076	0.348	1.075	0.501
Education level (Ref: Lower than high school level)						
High school level	0.925	0.348	0.976	0.781	0.968	0.798
Graduate level	1.022	0.807	0.996	0.965	1.083	0.552
Income quintiles (Ref: 1st quintile)						
2nd quintile	1.080	0.485	0.920	0.448	1.102	0.576
3rd quintile	1.276	0.034**	0.974	0.825	1.333	0.107
4th quintile	1.232	0.092*	0.988	0.925	1.446	0.05*
5th quintile	1.347	0.023**	0.902	0.459	1.422	0.078*
Living with partner	0.970	0.670	0.398	0.000***	0.719	0.008**
Number of resident children	1.335	0.000***	0.314	0.000***	0.728	0.006**
Number of difficulties with ADLs	1.069	0.000***	0.979	0.075*	0.970	0.06*
Illness duration (Ref: Less than a month)						
Less than a year	1.613	0.000***	2.497	0.000***	1.928	0.000***
More than a year	2.447	0.000***	2.914	0.000***	1.987	0.000***
Cause of death (Ref: Other)						
Cancer	1.355	0.001**	0.482	0.000***	2.632	0.000***
Heart, circulatory and blood conditions	0.910	0.240	0.497	0.000***	0.821	0.132
Allergies; hay fever; sinusitis; tonsillitis	0.555	0.000***	0.387	0.000***	0.817	0.217
Digestive system	0.459	0.000***	0.323	0.000***	0.896	0.545
Number of health insurance plans	0.835	0.001**	1.253	0.000***	1.022	0.784
Medicare FFS /Medicare HMO	1.082	0.332	1.173	0.078*	1.382	0.006**
Respondent had written end-of-life instructions	0.990	0.883	1.062	0.424	1.451	0.000***
Region (Ref: North-east)						
Midwest	1.496	0.000***	1.430	0.001**	2.047	0.000***
South	1.552	0.000***	0.965	0.724	1.964	0.000***
West	1.834	0.000***	1.317	0.024**	1.260	0.226
Wave (Ref: Wave 6)						
Wave 7	0.938	0.587	0.968	0.792	1.517	0.059*
Wave 8	0.923	0.496	0.989	0.929	1.758	0.009**
Wave 9	1.156	0.223	1.243	0.086	2.888	0.000***
Wave 10	1.072	0.561	0.913	0.482	3.317	0.000***
Wave 11	1.363	0.014**	1.122	0.407	3.085	0.000***
Wave 12	1.157	0.239	1.229	0.127	2.927	0.000***

Notes: Presented results are from multinomial logistic regression analysis. Results are presented as relative risk ratios (RRR), indicating percentage relative risk change for a unit increase in the observed variable compared to the referent group, holding other variables constant. Base outcome is 'Dying in hospital'. *P<0.1, **P<0.05, ***P<0.001. For categorical variables, reference category is stated in the row label, otherwise the reference is the complementary category.

Exhibit 4: Logistic regression analysis of determinants of end-of-life planning

Independent variable	Presence of living will					
	OR (Sample =6440)	P>|z|	OR (Sample =4334)	P>|z|	OR (Sample =6300)	P>|z|
Intercept	0.015	0.000***	0.020	0.000***	0.016	0.000***
Respondent ever discussed end-of-life care	3.329	0.000***	3.547	0.000***	3.316	0.000***
Race/ethnicity (Ref: Non-Hispanic white)						
Non-Hispanic black	0.310	0.000***	0.319	0.000***	-	-
Hispanic white	0.316	0.000***	0.316	0.000***	-	-
Other	0.563	0.021**	0.739	0.288	-	-
Religious adherence (Ref: Often)						
Sometimes	-	-	0.852	0.102	-	-
Never	-	-	0.846	0.041**	-	-
Religious importance (Ref: Very important)	-	-	1.314	0.011**	-	-
Race/ethnicity # Religious importance (Ref: Non-Hispanic white, religion very important)	-	-	-	-	-	-
Non-Hispanic white # Religion not important	-	-	-	-	1.131	0.167
Non-Hispanic black # Religion very important	-	-	-	-	0.313	0.000***
Non-Hispanic black # Religion not important	-	-	-	-	0.301	0.002**
Hispanic white # Religion very important	-	-	-	-	0.318	0.000***
Hispanic white # Religion not important	-	-	-	-	0.387	0.012**
Other # Religion very important	-	-	-	-	0.493	0.003**
Other # Religion not important	-	-	-	-	2.060	0.010**
Age	1.026	0.000***	1.028	0.000***	1.026	0.000***
Gender (Ref: Male)						
Female	1.109	0.096*	1.067	0.392	1.112	0.095*
Education level (Ref: Lower than high school level)						
High school level	1.323	0.000***	1.366	0.000***	1.341	0.000***
Graduate level	1.722	0.000***	1.725	0.000***	1.747	0.000***
Income quintiles (Ref: 1st quintile)						
2nd quintile	1.310	0.004**	1.240	0.073*	1.308	0.005**
3rd quintile	1.526	0.000***	1.445	0.003**	1.493	0.000***
4th quintile	1.646	0.000***	1.544	0.001**	1.620	0.000***
5th quintile	1.831	0.000***	1.534	0.002**	1.764	0.000***
Living with partner	0.678	0.000***	0.767	0.003**	0.689	0.000***
Number of resident children	0.817	0.001**	0.832	0.014**	0.824	0.002**
Number of difficulties with ADLs	1.053	0.000***	1.049	0.000***	1.054	0.000***
Illness duration (Ref: Less than a month)						
Less than a year	0.975	0.721	0.944	0.504	0.966	0.632
More than a year	1.146	0.058*	1.130	0.160	1.141	0.07*
Cause of death (Ref: Other)						
Cancer	1.241	0.014**	1.147	0.194	1.259	0.009**
Heart, circulatory and blood conditions	1.020	0.795	0.976	0.791	1.024	0.756
Allergies; hay fever; sinusitis;	1.156	0.147	1.093	0.463	1.192	0.082*

|						
tonsillitis						
Digestive system	1.118	0.350	1.066	0.657	1.168	0.200
Number of health insurance plans	1.233	0.000***	1.193	0.002**	1.232	0.000***
Medicare FFS /Medicare HMO	1.096	0.197	1.080	0.355	1.110	0.147
Region (Ref: North-East)						
Midwest	1.161	0.095*	1.125	0.285	1.184	0.064*
South	0.926	0.349	0.932	0.486	0.939	0.455
West	1.351	0.002**	1.344	0.015**	1.368	0.002**
Wave (Ref: Wave 6)						
Wave 7	1.125	0.257	-	-	1.159	0.169
Wave 8	1.286	0.016**	-	-	1.266	0.027**
Wave 9	1.206	0.073*	0.926	0.477	1.189	0.103
Wave 10	1.368	0.003**	1.039	0.724	1.359	0.004**
Wave 11	1.315	0.013**	0.977	0.835	1.295	0.021**
Wave 12	1.308	0.013**	1.008	0.943	1.305	0.016**

Notes: Presented results are from univariate logistic regression analysis. Results are presented as odds ratios, indicating percentage odds change for a unit increase in the observed variable, holding other variables constant. *P<0.1, **P<0.05, ***P<0.001. For categorical variables, reference category is stated in the row label, otherwise the reference is the complementary category.

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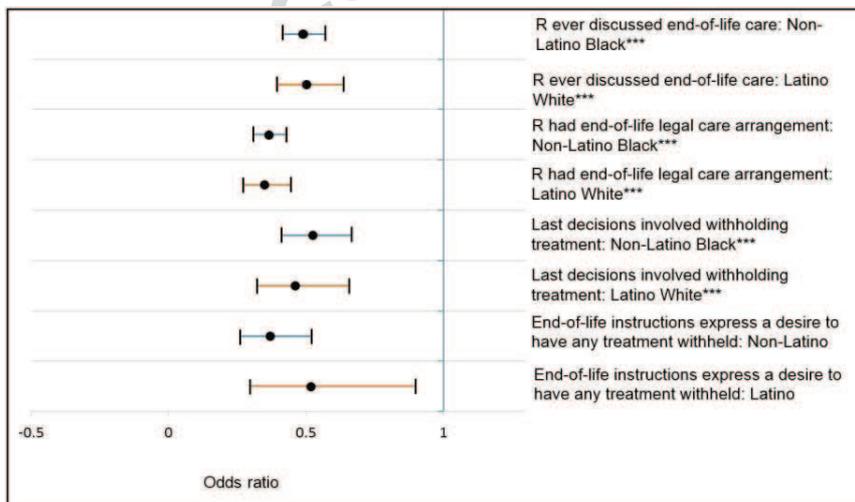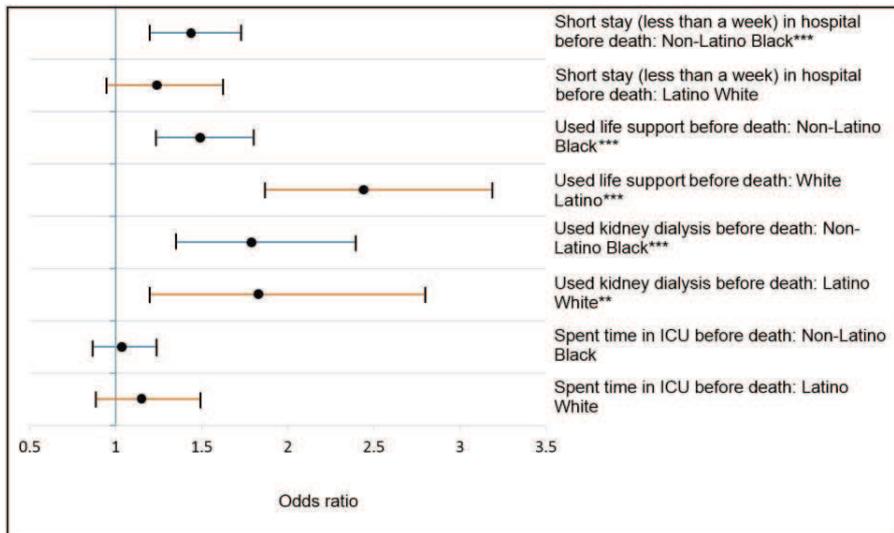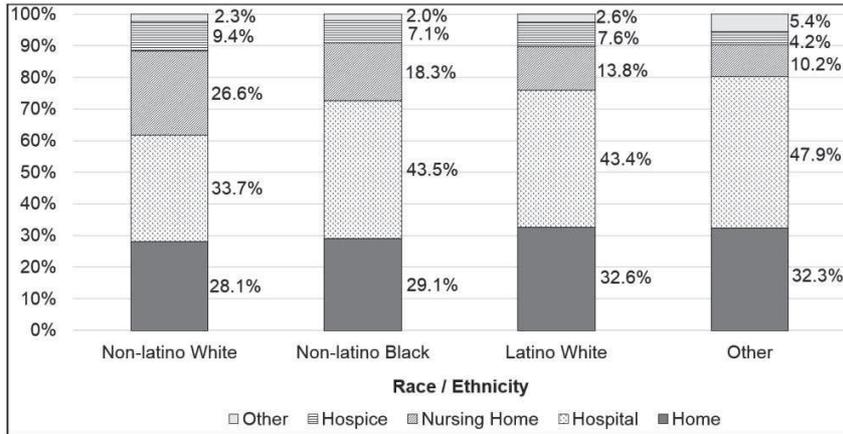
Highlights

- The study uses the Health and Retirement Study (HRS) – the largest longitudinal survey of a representative sample of Americans to examine nationwide cultural disparities in end-of-life care and planning from 2002 to 2014.
- This paper provides a comprehensive and up-to-date overview of end-of-life circumstances and planning for a representative sample of ethnically and racially diverse Americans.
- People from minority groups in the US are more likely to die in a hospital setting and have more intensive treatments at the end-of-life compared to white Americans. Also, individuals from minority ethnical and racial groups are less likely to engage in advance care planning activities and if they do so, significantly more likely to express a preference for intensive end-of-life care.
- More religious individuals are less likely to engage in end-of-life planning activities. Even though religion is an important factor in end-of-life planning, racial and ethnic differences persist.
- The observed disparities are significant over time, but have been narrowing between 2002 and 2014.
- Current policy and clinical practice should change to acknowledge heterogeneous values and needs of a culturally diverse population and to facilitate equitable access to required end-of-life care services for all.