

## Original Article

# End-of-Life Planning Depends on Socio-Economic and Racial Background: Evidence from the US Health and Retirement Study (HRS)

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## Abstract

**Context.** Americans express a strong preference for participating in decisions regarding their medical care, yet they are often unable to participate in decision-making regarding their end-of-life care.

**Objective.** To examine determinants of end-of-life planning; including, the effect of an individual's ageing and dying process, health status and socio-economic and racial/ethnic background.

**Methods.** US observational cohort study, using data from the Health and Retirement Study (1992 – 2014) including 37,494 individuals. Random-effects logistic regression analysis was used to examine the relationship between the presence of a living will and a range of individual time-varying characteristics, including time to death, and several time-invariant characteristics.

**Results.** End-of-life planning depends on several patient characteristics and circumstances, with socio-economic and racial/ethnic background having the largest effects. The probability of having a living will rises sharply late in life, as we would expect, and is further modified by the patient's proximity to death. The dying process, exerts a stronger influence on end-of-life planning than does the aging.

**Conclusions.** Understanding differences that increase end-of-life planning is important to incentivize patients' participation. Advance planning should be encouraged and accessible to people of all ages as it is inevitable for the provision of patient-centered and cost-effective care. *J Pain Symptom Manage* 2021;000:1–9. © 2021 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## Key Words

End-of-life, Living will, End-of-life planning, Advance care planning

## Trial Registration Number

Not applicable.

## Key Message

The study provides insight into the factors affecting of end-of-life planning based on a nationally representative longitudinal dataset of Americans, demonstrating that

end-of-life planning depends on a range of patient characteristics and circumstances, with socio-economic and racial/ethnic background being the most important.

## Introduction

Americans express a strong preference for being involved in decisions regarding their medical care.<sup>1</sup>

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However, evidence suggests that they are often unable to participate in decision making related to their end-of-life care.<sup>2</sup> Around 70% of decedents over 60 surveyed in the Health and Retirement Study (HRS) were not able to participate in those decisions<sup>3</sup>. Additionally, terminally ill individuals are often subjected to undesired and unhelpful treatments advocated by patients' carers or family members.<sup>4,5</sup> This demonstrates the importance of prospectively recording patients' wishes regarding intensive care in order to achieve goal-concordant care.

An advance directive is a legal document describing a patient's preferences regarding their medical care in case of incapacity, and is a key mechanism through which patients express their end-of-life care wishes. In the United States (US), this document can take two forms, either a living will or a durable power of attorney. The living will is a written statement containing people's preferences regarding future medical treatment in situations when they can no longer provide informed consent.<sup>1</sup> In contrast, a durable power of attorney gives decision-making power to a designated person who will decide on the patient's behalf, when the latter is incapable of making such decision.<sup>1</sup> Although written instructions about preferences for end-of-life care can go by various names, we use the term "living will" to refer to all such sets of instructions and consider it as a form of advance care planning. Evidence suggests that having an advanced directive is associated with better quality end-of-life care.<sup>6-8</sup>

Advance care planning can empower patients and assist physicians in providing goal-concordant care.<sup>9</sup> In the context of end-of-life care provision, the traditional doctor-patient relationship becomes more complicated as terminally ill patients may experience high levels of dependency and frailty which can limit their sovereignty and exaggerate the problem of asymmetric information.<sup>10</sup> Information asymmetry implies that the physician is better informed about the patient's health status and possible treatment pathways.<sup>11</sup> Often family members and carers become proxy decision-makers to represent the patients' interests and preferences, which additionally complicates the decision-making process, especially if the patient's preferences are unrecorded. Therefore, an advance care plan provides an opportunity to align the interests of the physician and the patient, making understanding factors that affect advance care planning critical.<sup>9,12</sup> Advance planning can be viewed as a type of health behavior, for which different individuals may have different motivation, facilitators and barriers.<sup>13</sup> Recently, however, scepticism about the value of advance care planning is increasing, since uptake remains low and evidence for advance care planning influencing patient outcomes is limited.<sup>14</sup> Therefore, it is important to understand determinants of advance care planning which could

determine the design and implementation of policies that encourage the uptake and engagement in such activities across various patient groups. A patient's prognosis or their subjective expectations regarding the imminence of death is one factor that could raise awareness of and encourage end-of-life planning. Thus, the aim of this paper is to examine the impact of socio-demographic factors, health status, age and proximity to death on advance care planning.

## Methods

### Sample

Our analysis uses a sample of 37,494 individuals from the Health and Retirement Study (HRS), surveyed biennially from 1992 through 2014. On average, each sample member appears about six times in the dataset. The HRS is a nationally representative longitudinal study of individuals over 50 years of age, designed to assess retirement and health among the elderly in the US.<sup>15</sup> It is a rich source of data organized into four major sections: health, work and retirement, social connections and income and wealth.

The surveys include "exit interviews," questionnaires completed by proxy respondents after a participant's death, identified from the social network of the deceased. The exit interview provides detailed information on the respondent's final year of life and death circumstances.

The first cohort of HRS participants was interviewed in 1992; since then five additional cohorts have been included in the panel study in order to replenish the study sample. Our data include any age-eligible individual interviewed at least once. The target population for study sample initially included all US residents aged 51 – 61 who live in households, later expanded (by 1998) to include the entire population aged 51 and older. Following conventional practice for population surveys, institutionalized individuals (prisons, jails, nursing homes, long-term or dependent care facilities) are excluded from the initial survey population, although they are retained if in subsequent interviews they have moved to a nursing home. Baseline interviews are conducted face-to-face, while follow-up interviews are mostly conducted via telephone. Since 2006, at each wave, half of the respondents complete the face-to-face while the other half complete the core interview by telephone. The half-samples alternate waves so there is an in-person interview for each respondent every four years.

### Analysis

The presence of a living will is our outcome measure and it is used as an indicator of advance care planning.

Beginning in 2002 a question regarding whether the deceased had written end-of-life instructions was included in the exit interview. Because the timing of end-of-life instructions was included in the questionnaire, we were able to reconstruct the presence of these for deceased participants prior to their death. For deceased participants without written end-of-life instructions we assumed that these were also not available at the times of previous interviews. Further, from 2012, the core HRS questionnaire included a question regarding the presence of the living will. If a living participant gave a negative response, then we assumed that the participant did not have a living will in all previous waves. In contrast, if a living participant confirmed the existence of a living will, we coded data in all previous waves as missing, as we were not sure when the end-of-life instructions were written. About 33% of deceased participants and 20% of living participants had a living will.

Ageing was represented using both: chronological age and remaining lifetime, with the latter serving as proxy for biological age. As people age, they are more aware that the end of their life is approaching. The aging process can be characterized through chronological age, which refers to amount of time the person has been alive, or through biological age, which refers to how old the person seems and which is related to genetic, behavioral, and environmental conditions.<sup>16</sup> Biological age can be characterized using various biomarkers of ageing, but these are not routinely measured in population-level studies. On the other hand, if individuals are followed longitudinally, some will die during a follow up period. Remaining lifetime, or time to death (TTD) can be used as a proxy for biological age.<sup>17</sup> Research has shown that individuals' expectations regarding their own future survival agree with actual experience, demonstrating that biomarkers were predictive of TTD regardless of age.<sup>18–21</sup> The idea of using TTD in describing patients trajectories first appeared in 1970s and focused on hospital care of terminally ill patients.<sup>22</sup> Later, few other studies considered TTD in assessing disability and classifying dying patients.<sup>17,23</sup> Despite that, most studies take into account only chronological age, while ignoring the impact of TTD on late life events.

A problem with TTD in panel studies is that for living participants it remains unknown, because only in rare occasions the sample will be followed up until all individuals die, removing the right-censoring problem.<sup>17</sup> Still, it can be estimated. Information on participants' month and year of birth, death (if applicable), and month and year of interviews was used to establish measures of age and TTD at each interview. All age variables were expressed relative to age 75. For those who died during the follow up period, TTD is known and can never exceed 22 years. Participants that remain

alive at the end of the follow up period have an unobserved value of TTD at each interview. We used interval regression to model remaining lifetime and to provide a basis for imputing the unobserved (censored) values of TTD. For cases with unknown a value of TTD, we constructed variables for lower and upper bounds of TTD. For cases with censored TTD, the lower bound of TTD is always known. For example, for someone still alive in 2014, we know that TTD is greater than 22 in 1992, and TTD is greater than 20 in 1994, and so on. So, at each interview the lower bound of TTD presents a difference between the age at final interview and the age at the current interview. We also assumed that the maximum possible age of participant is 112 years, as this was the age of the oldest deceased participant in the sample. The upper bound of TTD at each wave is defined as the difference between the maximum possible age and the current age of participant at each interview. Our interval regression for remaining lifetime imposes these bounds; when TTD is known (among uncensored cases) the upper and lower bounds are identical. Explanatory variables used in the regression include age, gender, indicator for racial and ethnicity status (Non-Hispanic White, Non-Hispanic Black, Hispanic White and Other), education level (below high-school level, high-school level, degree level), total assets, marital status (married or partnered, not-married or not-partnered), smoking and drinking status, self-reported health, census region (Midwest, Northwest, South, East and Other), and indicators for the following medical conditions: high blood pressure, diabetes, cancer, lung disease, heart disease, stroke, arthritis and psychiatric problems. These conditions are the most common comorbidities among the elderly.<sup>24</sup> The estimated regression was used to impute TTD to the censored observations, with the known lower- and upper-bound conditions imposed. Because we are using a linear model of remaining lifetime, it produces an unbiased estimate of the expected value of remaining lifetime among those for whom TTD is not observed.

We used random-effects logistic regression to estimate the relationship between the probability of having a living will and a set of time-varying and time-invariant control variables. To account for the uncertainty present in the TTD imputation process, we performed five independent sets of imputations, and used multiple imputation estimation and inference techniques in the analysis. Explanatory variables included age and TTD in linear and quadratic form, gender, indicator for racial and ethnicity status, education level, marital status, income and assets, census region, and indicators for excellent self-reported health (health status is very good or excellent), and the presence of the eight medical conditions listed above. All analyses were performed using the statistical software STATA (Version 14).

## Results

On average, individuals were 66 years old over the 12 survey waves (Table 1). Average estimated TTD for the analyzed sample was 16.3 years, while average observed TTD for individuals with observed deaths was 7.2 years. Majorities of the sample were non-Hispanic Whites (72.8%), female (60.3%) and had a high-school degree or more (73.2%). Arthritis was the most common chronic condition reported by 49.3% of participants, while stroke was the least common condition, reported by only 5.7% of the sample. Table 1

A range of individual characteristics affected the presence of the living will (Table 2). Age [OR (Age) = 1.85, 95%CI (1.81 – 1.90),  $P < 0.001$ ; OR (Age<sup>2</sup>) = 0.99, 95%CI (0.986 – 0.988),  $P < 0.001$ ], TTD [OR (TTD) = 0.73, 95%CI (0.69 – 0.76),  $P < 0.001$ ; OR (TTD<sup>2</sup>) = 1.01, 95%CI (1.008 – 1.012),  $P < 0.001$ ] and racial and ethnic background [OR (Non-Latino Black) = 0.002, 95%CI (0.002 – 0.004),  $P < 0.001$ ; (OR (Latino White) = 0.002, 95%CI (0.001 – 0.005),  $P < 0.001$ ] are significantly associated the probability of having a living will. Non-Hispanic Whites had significantly higher probability of engaging in end-of-life planning activities, compared to individuals of other racial and ethnic background. Moreover both educational attainment [OR (High school level) = 30.49, 95%CI (19.3 – 48.1),  $P < 0.001$ ; OR (Graduate level) = 165.2, 95%CI (103.3 – 264.2),  $P < 0.001$ ] and economic well-being [OR (Linearized income) = 1.65, 95%CI (1.47 – 1.85),  $P < 0.001$ ], were important factors in having a living will. In general, individuals of higher social status were more likely to have a living will. Also, the probability was higher for individuals of poorer health [OR (Difficulties with ADLs) = 1.42, 95%CI (1.32 – 1.53),  $P < 0.001$ ] and females [OR = 3.41, 95%CI (2.42 – 4.78),  $P < 0.001$ ], but lower for those living with a partner [OR = 0.45, 95%CI (0.35 – 0.59),  $P < 0.001$ ]. Cancer [OR = 1.77, 95%CI (1.46 – 2.14),  $P < 0.001$ ] in particular had a strong effect on the probability on having a living will. Other chronic conditions such as high-blood pressure [OR = 1.20, 95%CI (1.06 – 1.34),  $P = 0.004$ ], lung disease [OR = 1.20, 95%CI (1.01 – 1.41),  $P = 0.034$ ] were also associated with having a living will. However, the presence of diabetes, stroke and psychiatric problems were not associated with having a living will. Table 2

As individual end-of-life planning trajectories depend both on age and TTD, there are numerous pathways in progress within the general population at any moment. We illustrate selected scenarios in Fig. 1 and show how they are modified by various background factors in Figs. 2 and 3. In all cases, the fitted probabilities reflect the mix of sample characteristics in all other respects. Fig. 1 illustrates the pattern of having a living will for individuals who die at age 80, 90 and 100, depending on current age. Individuals who die at a

Table 1  
Sample Characteristics

	Sample Mean / %	Standard Deviation
Time-variant characteristics		
Age	66.29	11.37
TTD (imputed)	16.32	6.16
TTD (observed)	7.16	5.01
Income		
Total income	\$67,853	\$162.17 (S.E.) <sup>a</sup>
Missing	6.70%	
Assets		
Total assets	\$483,137	\$856.45 (S.E.) <sup>a</sup>
Missing	4.32%	
High blood pressure		
Yes	49.43%	-
Missing	2.84%	-
Diabetes		
Yes	15.34%	-
Missing	3.43%	-
Cancer		
Yes	9.87%	-
Missing	2.76%	-
Lung disease		
Yes	7.34%	-
Missing	4.54%	-
Heart disease		
Yes	16.51%	-
Missing	2.45%	-
Stroke		
Yes	5.65%	-
Missing	3.55%	-
Psychiatric problems		
Yes	13.12%	-
Missing	6.71%	-
Arthritis		
Yes	49.31%	-
Missing	4.76%	-
Having difficulties with ADLs		
Yes	11.12%	-
Missing	3.21%	-
Self-reported health excellent		
Yes	42.25%	-
Missing	4.68%	-
Time-invariant characteristics		
Gender		
Female	60.25%	-
Male	39.75%	-
Missing	0.00%	-
Race/ethnicity		
Non-Latino White	72.83%	-
Non-Latino Black	15.89%	-
Latino White	7.45%	-
Other race/ethnicity	3.83%	-
Missing	0.00%	-
Cohabitation status		
Living with partner	63.39%	-
Not living with partner	34.27%	-
Missing	2.34%	-
Education		
Lower than high school level	26.73%	-
High school level	51.57%	-
Graduate level	21.60%	-
Missing	0.10%	-
Region		
Northeast region	16.01%	-
Midwest region	24.09%	-
South region	40.49%	-
West region	12.27%	-
Other region	0.14%	-
Missing	0.00%	-

TTD denotes = time-to-death, ADL = activities of daily living.

<sup>a</sup>S.E. denotes standard error. Variables "Total income" and "Total assets" are highly skewed, so standard error is a more appropriate measure of dispersion. The values are averaged over the pooled sample of 37,494 individuals and 226,545 person-wave observations.

Table 2  
Random-Effects Logistic Regression Analysis of Determinants of Planning at the End-of-Life

Independent Variable (N= 33,172)	Presence of the Living Will Odds Ratios (95% CI)	PValue
Intercept	0.010 (0.000 – 0.020)	<0.001***
TTD	0.725 (0.693 – 0.758)	<0.001***
TTD <sup>2</sup>	1.010 (1.008 – 1.012)	<0.001***
Age	1.853 (1.808 – 1.899)	<0.001***
Age <sup>2</sup>	0.987 (0.986 – 0.988)	<0.001***
Gender (Ref: Male)	3.410 (2.431 – 4.782)	<0.001***
Race/ethnicity (Ref: Non-Latino White)		
Non-Latino Black	0.002(0.002 – 0.004)	<0.001***
Latino White	0.002 (0.001 – 0.005)	<0.001***
Other	0.004 (0.001 – 0.012)	<0.001***
Living with partner	0.452 (0.348 – 0.589)	<0.001***
Linearized total income	1.647 (1.469 – 1.847)	<0.001***
Total assets	1.003 (1.002 – 1.004)	<0.001***
Education level (Ref: Lower than high school level)		
High school level	30.487 (19.330 – 48.083)	<0.001***
Graduate level	165.181 (103.276 – 264.191)	<0.001***
High blood pressure	1.199 (1.060 – 1.355)	0.004**
Diabetes	1.143 (0.966 – 1.353)	0.119
Cancer	1.766 (1.458 – 2.139)	<0.001***
Lung disease	1.195 (1.013 – 1.409)	0.034**
Heart disease	0.902 (0.808 – 1.008)	0.068*
Stroke	1.071 (0.883 – 1.299)	0.487
Psychiatric problems	1.094 (0.957 – 1.251)	0.190
Arthritis	1.113 (0.988 – 1.254)	0.078*
Number of difficulties with ADLs	1.421 (1.320 – 1.530)	<0.001***
Self-reported health excellent (Ref: Self-reported health is below excellent)	0.945 (0.790 – 1.129)	0.532
Region (Ref: North-east)		
Midwest	2.491 (1.541 – 4.027)	<0.001***
South	1.205 (0.780 – 1.861)	0.400
West	4.545 (2.643 – 7.815)	<0.001***
Other	0.950 (0.028 – 32.388)	0.977

Notes: Presented results are from random effects logistic regression analysis. Results are presented as odds ratios. Odds ratio indicates percentage odds change for a unit increase in the observed variable, holding other variables constant. For categorical variables, the reference category is stated in the row label, otherwise the reference is the complementary category. Total income values and total asset values were divided by 100,000 to aid interpretation.

\*  $P < 0.1$

\*\*  $P < 0.05$

\*\*\*  $P < 0.001$ . N denotes sample size.

very old age (e.g. 100 years) will almost certainly have a living will immediately prior to death (97.5%), while the analogous probability for individuals who die at age 80 is much lower (38.1%). Lastly, most individuals don't initiate a living will until age 75 or older. Fig. 1

Non-Hispanic Whites initiate end-of-life planning much earlier compared to those of other ethnic and racial backgrounds, and also end up with much higher levels of participation (Fig. 2). For example, Non-Hispanic Whites dying at age 100 will almost certainly have a living will (99.2%), while the same probability among Non-Hispanic Blacks dying at the same age is much lower (37.5%). The differences are even larger for individuals who die younger, indicating the importance of ethnicity and race for end-of-life planning. Fig. 2

More educated individuals are more likely to participate in end-of-life planning and, on average, do so earlier compared to their less-educated counterparts (Fig. 3). The differences are particularly high for individuals who die younger. For example, a college-educated individual who dies at age 80 years has 79.1%

probability of having a living will, while someone with only a basic education dying at the same age has only a 2.4% probability of having a living will. Fig. 3

## Discussion

The study provides insights into factors that affect advance care planning. Our results, based on a nationally representative sample of Americans, provide key insights into factors that indicate variation in how and when Americans perform advance care planning. We show that despite concerted efforts to push advance care planning upstream, few individuals undertake advance care planning before the age of 75, and only about a third of patients who die at age 80 adopt an advance care plan. Furthermore, while patients with cancer are most likely to have an advance care plan, patients with heart disease, the most common cause of death in the US, are least likely to have an advance care plan.

Our results provide unique insights into how biological and chronological age are associated with advance

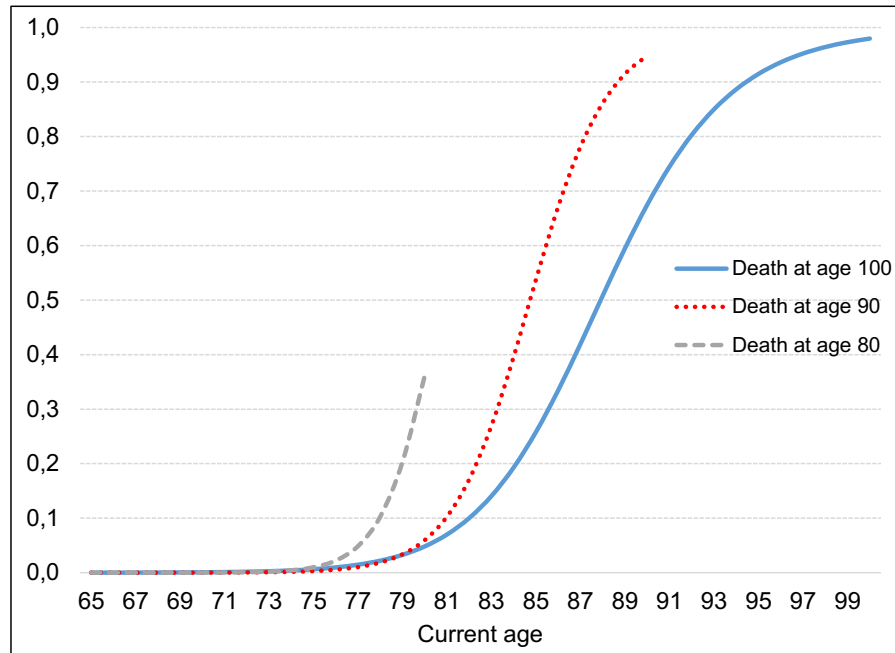


Fig. 1. Probability of having a living will, by current age and age at death. Notes: The graph depicts an average sample population for different ages at death. For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.

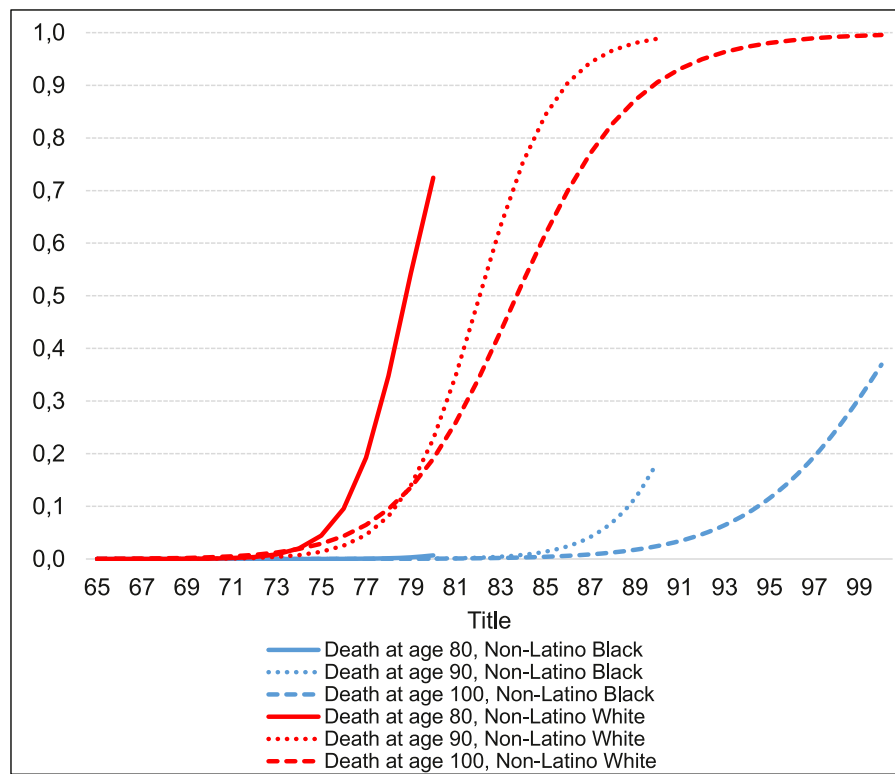


Fig. 2. Probability of having a living will, by current age and age at death for individuals of different ethnic and racial background. Notes: The graph depicts an average sample population of different ethnic and racial background for different ages at death. Effect of Non-Latino Black is similar to the effect of Latino White and therefore trajectories of Non-Latino Black are indicative of those of Latino White. For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.

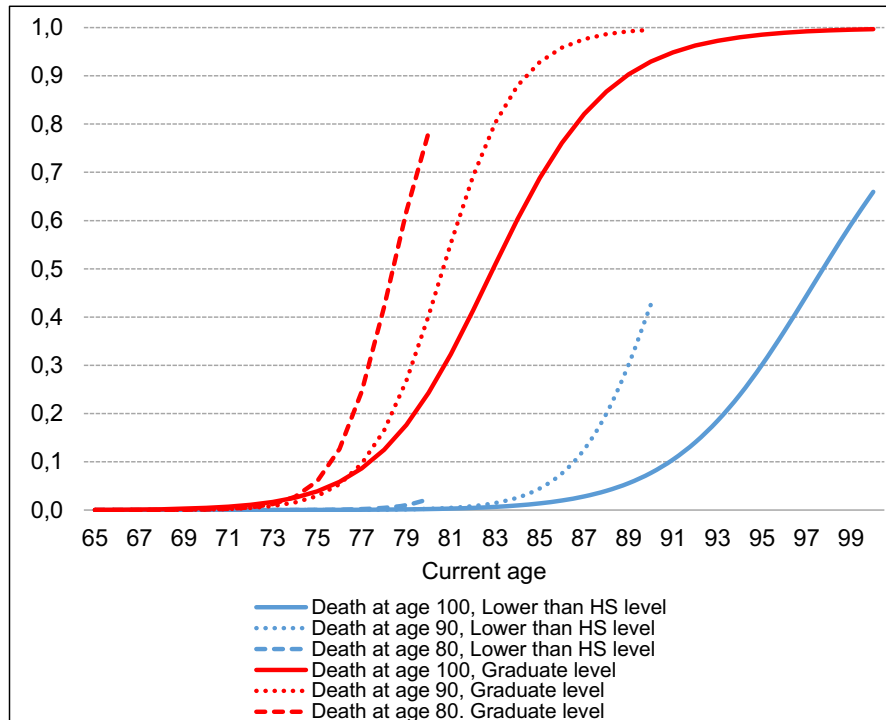


Fig. 3. Probability of having a living will, by current age and age at death for different educational levels. Notes: HS denotes “high-school”. The graph depicts an average sample population that has different levels of educational attainment for different ages at death. For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.

care planning. If TTD is viewed as a proxy for biological age, our results indicate that it is chronological age, and not biological age, that exerts a stronger influence on the likelihood of having a living will.<sup>17</sup> Further, worsened health status is also positively correlated with participation in end-of-life planning. However, even though aging and health status matter, an individual’s socio-economic and racial/ethnic circumstances appear to have a strong association with the propensity to plan for the end-of-life. Non-Hispanic Whites and more educated Americans have considerably higher rates of end-of-life planning participation.

Serious illnesses significantly increase someone’s likelihood of having a living will though not all diseases have a similar impact. A cancer diagnosis is often presented to a patient as a “death sentence,” and may be accompanied by a prognosis regarding remaining lifetime likely prompting patients without living wills to consider adopting one. Additionally, as cancer patients tend to have better access to palliative services, they may also have a better awareness of end-of-life planning options and their significance.<sup>25</sup> However, patients with heart disease, the most common cause of death in the US, are least likely to have an advance care plan, suggesting opportunities to improve care and communication for this large group of patients. Prior work has shown that both patients with heart disease and their

physicians are likely to underestimate their risk of mortality compared to cancer, which could reduce their likelihood of documenting an advance care plan since it alters their perceived time to death.<sup>26,27</sup>

Our results are consistent with recent studies on end-of-life planning.<sup>28,29</sup> Older individuals and those in poorer health are more aware that death is approaching and are more inclined to engage in care planning activities that could relieve pain and discomfort in their last moments of life.<sup>1</sup> However, few studies consider both age and remaining lifetime simultaneously, suggesting that the dying process is more influential than aging process as a determinant of end-of-life planning.<sup>17</sup> Our results suggest that proximity to death, and not just chronological age, is one of the strongest drivers of health care utilization at the end-of-life.<sup>30,31</sup>

Having an advance care plan affects patient outcomes. Individuals with recorded end-of-life preferences are less likely to utilize intensive, out-of-hospital institutional care at end of their lives.<sup>32</sup> Evidence also suggests that having an advance plan increases the likelihood of fulfilling the patients’ preferences regarding their end-of-life care<sup>8</sup> and improves their satisfaction and quality of life in their final weeks of life.<sup>7</sup> End-of-life planning may help to align the interests and minimize disputes between the principal (patient) and the agent (physician). It can prevent overutilization, and

diminish futile treatments at the end-of-life ensuring that resources are used in more cost-effective ways.<sup>33</sup>

In the US, advance care planning has been widely promoted as a tool for communicating end-of-life preferences.<sup>34</sup> Despite these efforts, completion rates remain low. According to a recent systematic review, only about one third of Americans has completed some form of advance care planning.<sup>34</sup> Since 2016 Medicare reimburses physicians for having end-of-life conversations, and early evidence suggests that these conversations are associated with less intensive end-of-life care.<sup>35</sup> Also, advance care planning includes several legal conditions, required for executing advance directives, such as qualified witnesses and notarization.<sup>34</sup> Even though these restrictions are put in place to protect the patients, these can also be barriers for those that might not fully understand the legal system and cannot afford legal counselling.

This study has several limitations. The analysis utilizes exit interviews which are conducted with a proxy respondent, which might lead to missing or erroneous information regarding the existence and content of living wills. Nevertheless, most proxy-respondents (88%) are close family members and they are likely aware of care planning activities of their loved ones. Further, family and health care professionals may have an important role in individual's end-of-life decision-making, but unfortunately the used data does not allow investigations of their impact to end-of-life decisions and living will content. Also, it was not possible to assess the patient's quality of end-of-life or family satisfaction with the patient death quality and to investigate the relationship between having a living will and the end-of-life care model (e.g. ICU or palliative care). Another potential weakness is the imputation of TTD. While we used an extensive set of possible predictors, we cannot exclude a possibility of unobserved heterogeneity that could bias our estimates. Finally, even though our random-effects logistic model controls for a wide range of individual characteristics that may affect advance care planning, some important determinants might remain unobserved. Therefore, our findings should be interpreted as associations and not as causal effects.

Advance care planning is an important step for the provision of patient-centred and cost-effective care.<sup>36</sup> Since the US is racially and ethnically diverse, initiatives should also be culturally tailored to acknowledge different attitudes and motivation towards advance planning. In addition, advance care planning can serve as an instrument to accelerate a change in attitudes towards death and dying, moving away from traditional medical paternalism.<sup>37</sup> Also, this can assist in reducing information asymmetry in the doctor-patient relationship and facilitate informed decision-making. Planning for the end-of-life can have a significant effect on the care

patients receive in their last moments.<sup>3</sup> Policies should be aimed not only at patients and healthcare professionals, but also at close family members and caregivers to incentivize patients to express and record their end-of-life preferences. This may reduce decision-making conflicts and minimize the risk of overtreatment as well as the provision of unwanted and futile care. It can also contribute to a more rational use of scarce healthcare resources and lower societal burden.

Patient autonomy is increasingly becoming a central ethical principle in healthcare decision-making. Policy makers need to favor policies that empower patients and increase their participation in advance care planning. These policies should be aimed at patients of all ages, not only to older adults, as proximity to death and not just chronological age is an important factor in end-of-life planning.

## Conclusion

This study presents robust findings on the factors affecting advance care planning in the US and suggests that planning depends on a range of patient characteristics and circumstances, with socio-economic and racial/ethnic background, TTD and health status being the most significant ones. The chances of having a living will rise sharply late in life, as we would expect, but are further modified by the patient's proximity to death. Providing the right care, at the right moment, and according to patients' preferences is the ultimate goal of high-quality end-of-life care and advance care planning is a step forward in the achievement of that goal.

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