## Title

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## Journal

Journal of the American Geriatrics Society, 71(10)

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## Publication Date

2023-10-01

## DOI

10.1111/jgs.18498

Peer reviewed

HHS Public Access

Author manuscript

*J Am Geriatr Soc*. Author manuscript; available in PMC 2024 October 01.

Published in final edited form as:

*J Am Geriatr Soc*. 2023 October ; 71(10): 3244–3253. doi:10.1111/jgs.18498.

# Disparities in Advance Care Planning Among Older US Immigrants

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## Abstract

**Background:** Despite known racial disparities in advance care planning (ACP), little is known about ACP disparities experienced by US immigrants.

**Methods:** We used data from the 2016 wave of the Health and Retirement Study. We defined ACP engagement as self-reported end-of-life (EOL) discussions, designation of a power of attorney (DPOA), documented living will, or "any" of the three behaviors. Immigration status was determined by respondent-reported birth outside the US. Time in the US was calculated by subtracting the year of arrival in the US from the survey year of 2016. We used multivariable logistic regression to estimate the association between ACP engagement and immigration status and the relationship of acculturation to ACP engagement, adjusting for sociodemographics, religiosity, and life expectancy.

**Results:** Of the total cohort (N=9928), 10% were immigrants; 45% of immigrants identified as Hispanic. After adjustment, immigrants had significantly lower adjusted probability of any ACP engagement (immigrants: 74% vs US-born: 83%, p<0.001), EOL discussions (67% vs 77%, p<0.001), DPOA designation (50% vs 59%, p=0.001) and living will documentation (50% vs 56%, p=0.03). Among immigrants, each year in the US was associated with a 4% increase in the odds of any ACP engagement (aOR 1.04, 95% CI 1.03–1.06), ranging from 36% engaged 10 years after immigration to 78% after 70 years.

**Conclusion:** ACP engagement was lower for US immigrants compared to US-born older adults, particularly for those that recently immigrated. Future studies should explore strategies to reduce disparities in ACP and the unique ACP needs among different immigrant populations.

## INTRODUCTION

Immigrants are projected to represent nearly one in four adults aged 65 and older by 2060 due to the aging of long-term immigrants and an increase in recent migration of older

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Conflicts of Interest: AK reports grants from Humana Inc. and receives personal consulting fees from Papa Health outside of the submitted research.

adults.[1] Younger and middle-aged immigrants on average have health and mortality benefits along multiple indicators (the so-called “healthy migrant effect”), including a 2.4-year life expectancy advantage at age 65, that eventually converges with native levels within 10–20 years of residence in the US.[2] In contrast, older immigrants more frequently report worsened health immediately after immigrating, and can experience persistent language and cultural barriers.[3,4] This can be detrimental to preserved independence, quality of life, and engaging with the health care system.[3–5] Demographic shifts within the immigrant population are notable. Currently, most older immigrants are from Latin America (38%), followed by Asia (31%), and Europe (24%). However, the proportion of older Asian immigrants is rising with higher rates of recent arrivals, particularly among those over age 65.[6,7]

Immigrants have different patterns of care at the end-of-life (EOL), including a greater likelihood of intensive treatments and death in the intensive care unit—especially among recently migrated—and potentially goal-discordant care among those with advanced cancer.[8,9] However, whether these patterns represent true health disparities, as opposed to differences in preference, is debated.[10,11] For example, among some racial and ethnic groups with high overlap with immigrant populations, there are documented preferences for life-prolonging or intensive treatment courses at the end of life.[12,13] Consequently, understanding immigrant engagement with advance care planning (ACP), the process to prepare for and guide care at the EOL, may provide insight into potential disparities among older immigrants.

Prior studies that examine the prevalence of ACP engagement among immigrants are limited by small sample size, representation of a single racial or ethnic group, or operationalization of a narrow definition of ACP that focused on code status designation and does not include discussions about goals and values or surrogate designation.[14,15] In addition, studies have not consistently differentiated foreign-born, first-generation immigrants from US-born second-generation immigrants who may have substantially different preferences and resources grounded in unique experiences of migration, such as acculturation. Acculturation, which captures the adoption of new values and behaviors, appears to initially confer an advantage of lower mortality and better self-rated health compared to US-born counterparts that decreases with time spent in the US.[16] Studies examining the relationship between time spent in the US, a common proxy measurement of acculturation, and ACP engagement in diverse, nationally representative samples are lacking.[17]

To deepen the understanding of disparities with ACP, this study relies on a large, nationally representative diverse cohort of older adults in the US which contains information on immigrant status, time since immigration, and broad measures of ACP engagement. We have two objectives: 1) to determine the prevalence of ACP engagement among older adult immigrants in the US compared to their US-born counterparts, and 2) to describe the relationship between ACP engagement and time spent in the US.

# METHODS

## Data Source and Study Sample

This study uses cross-sectional data from the 2016 wave of the Health and Retirement Study (HRS). The HRS is a longitudinal survey of community-dwelling individuals over age 50 interviewed biennially until death, with "refresher" cohorts added every six years to account for aging of the original 1998 cohort.[18] The survey employs a multistage probability sample of the United States with oversampling of Black, Hispanic, and female individuals to ensure a nationally representative cohort, and is conducted in English and Spanish.[19] The present study includes 9,928 adults that were age-eligible (≥65+) at the time of the 2016 wave to be asked questions regarding ACP and were not missing information on immigration status (n=10).

## Immigration status and Time Spent in the US

Immigration status was determined by asking respondents if they were born outside the US and categorized as US-born or immigrant. If born outside of the US, respondents were further asked the year and age of arrival in the US. Time in the US since migration was calculated by subtracting the year of arrival in the US from 2016, the survey year.[16,20]

## ACP Measures

This study measured a broad range of ACP engagement using three questions inquiring if the respondent: (1) ever discussed with anyone the care or medical treatment desired if the respondent became seriously ill in the future ("Discuss end-of-life care (EOLC)"); (2) ever legally arranged for a specific person to make decisions about care or medical treatment (durable power of attorney, "DPOA"); or (3) ever provided written instructions about the care or medical treatment (living will, "LW").[21–23] Only respondents affirming living wills were asked on follow-up if the living will expressed a desire to limit care or medical treatment received. In addition to examining each individual ACP engagement behavior, we categorized individuals as participating in "any ACP" engagement if there was an affirmative response to any of the three questions ACP engagement questions. If respondents had previously answered any of these questions in earlier survey waves, respondents were provided the opportunity in the 2016 wave to update their response.

## Sociodemographic, clinical, and functional subgroups

We included several covariates with known associations to ACP engagement and immigrant status. Covariates included age, gender, marital status, number of children living at home, religious service attendance frequency, total assets, and attainment of at least a bachelor's degree.[24,25] We included self-reported race and ethnicity using the original survey categories of White, Black, Hispanic, and "Other," which includes American Indian, Alaskan Native, Asian, Pacific Islander, and any other unlisted self-identified racial category. Respondent-level racial and ethnic categories contained in the "Other" category were not available for this analysis due to masking to preserve respondent confidentiality.

To account for clinical and functional status covariates, we adjusted for the Lee prognostic index, a measure of 4- and 10-year life expectancy. Validated in the HRS, the 12-item

prognostic index captures a variety of health conditions, behaviors, and limitations in functional status that clinicians can use for targeted advance care planning.[26–28]

### Statistical Analysis

We first used descriptive statistics, including adjusted Wald tests to compare the prevalence of ACP engagement between US-born and immigrant older adults (Table 1). Multivariable logistic regression models were then used to determine the adjusted probability of each ACP engagement behavior by immigrant status (Figure 1). In all models, we adjusted for sociodemographic characteristics and the prognostic index. Notably, we did not adjust for language of survey administration (either English or Spanish) as a covariate due to the high correlation (correlation = 73%) between Spanish survey administration and Hispanic immigrant status. We conducted a sensitivity analysis stratifying all analyses by race/ethnicity given the correlation between race/ethnicity and immigrant status (Table 2).

We then used multivariable logistic regression within the immigrant subset (N=1,177) to determine the association of years since immigration to the US and each ACP behavior (Figure 2). Linear, quadratic, and cubic functional forms of the relationship between years in the US and each ACP behavior were tested. We present adjusted probabilities derived from the multivariate regression models. All statistical analyses were conducted in Stata (SE 17) and made use of survey weights to ensure national representativeness and improve variance estimations due to complex survey design.

## RESULTS

Approximately 90% of older adults were classified as US-born and 10% as immigrants (Table 1). The median age of the US-born subset was 75 (IQR 69–81), and they identified as 55% female, 85% non-Hispanic white, 9% Black, 4% Hispanic, and 2% “Other”. The median age of the immigrant subset was 75 (IQR 68–80), and they identified as 58% female, 45% Hispanic, 35% White, 8% Black, and 12% “Other.” Immigrants reported lower engagement in “any” ACP behaviors compared to US-born (Immigrants: 63% vs US-born: 84%, $p<0.001$, Table 2). This included discussion about care at EOL (56% vs 78%, $p<0.001$), designation of a DPOA (42% vs 60%, $p<0.001$), and having a living will (38% vs 57%, $p<0.001$). Among those who reported having living wills, both US-born and immigrant adults had a high prevalence of living wills with respondent’s preference to limit care at EOL (93% vs 94%, $p=0.81$).

After adjustment for sociodemographic characteristics, health characteristics, religiosity, and life expectancy, immigrants remained less likely to have engaged in ACP. Compared to US-born older adults, adjusted probability of ACP engagement was lower for discussions about care at EOL (immigrants: 67% vs US-born: 77%, $p<0.05$), DPOA (50% vs 59%, $p<0.05$), presence of a living will (50% vs 56%, $p<0.05$), and any ACP (74% vs 83%, $p<0.005$) (Figure 1). The adjusted probability of limiting care in a living will was the same between the groups (94% vs 94%, $p=0.55$).

We then conducted all analyses within each racial and ethnic sub-group (Table 2). We found consistently lower odds of any ACP engagement for immigrants compared to US-born older

adults within each racial/ethnic sub-group. Black immigrant respondents, compared to their US-born counterparts, had the lowest odds of any ACP engagement (aOR: 0.47, 95% CI 0.32–0.68), followed by Hispanic respondents (aOR: 0.50, 0.35–0.72), "Other" respondents (0.65, 0.25–1.69), and White respondents (aOR: 0.69, 0.46–1.02). Similar patterns held for discussions about care at EOL, DPOA, and living wills.

We next examined the association of years in the United States since immigration with ACP behaviors among the immigrant sample. In this sample (n=1,177), the mean years spent in the US was 48 years (range 7–93) with mean age at arrival of 27 (range 0–73). While holding age, sociodemographic factors, and health characteristics constant, the adjusted probability of any ACP engagement among immigrants was 29% 5 years after migration 67% after 50 years, and 83% after 75 years (Figure 2A). The pattern of adjusted probabilities was similar for discussion about care at EOL (Figure 2B), DPOA designation (Figure 2C), and having a living will (Figure 2D). The red lines in each figure indicate the level of ACP engagement of US-born older adults as a reference; notably after several decades in the United States, immigrants reach a nearly equivalent ACP engagement level.

## DISCUSSION

In a large, nationally representative sample of diverse older US adults, immigrants compared to US-born older adults had a substantially lower prevalence of ACP engagement, broadly defined as discussions about care at EOL, designation of power of attorney, and living will. These findings are consistent with prior literature from smaller studies.[14] Notably, our large cohort allowed for the most detailed assessment of ACP engagement among immigrants within different racial/ethnic backgrounds to date, and showed lower ACP engagement particularly among Black and Hispanic immigrants. ACP engagement increased with years spent in the US, indicating ACP may be tied to the acculturation process, and perhaps as much a cultural activity (i.e. becoming acclimated to the US Health care system) as a health activity. Results draw attention to the need for clinicians to address disparities in ACP as a possible strategy to prepare older immigrant adults and their proxies for future decision-making at end-of-life.

Results indicate that although immigrants were less likely to report having engaged in ACP, the difference was attenuated after accounting for sociodemographic covariates. The extent that socioeconomic differences between immigrant and US-born older adults explain the lower prevalence of ACP engagement among older immigrants in the US likely reflect a health care disparity, a pattern true for all measured types of ACP engagement. Strikingly, among those that reported having completed a living will, nearly all immigrants expressed a desire to "limit care" at EOL at the same level as US-born older adults. If preferences among older immigrant and US-born adults are not widely different, then this strengthens the potential for a health care disparity. Alternatively, residual differences in completion of living wills may reflect a degree of differences in preference by older immigrant adults.

In addition, we found that ACP engagement of immigrant older adults strongly depended on self-reported race and Hispanic ethnicity. Among self-identified White respondents, ACP engagement was high regardless of immigration status (86% vs 85%). Though

not statistically significant, adjustment of sociodemographic factors widened rather than narrowed this difference for White respondents, who are a group of overall high socioeconomic status among both immigrant and US-born older adults. In contrast, self-identified Black and Hispanic immigrants had substantially lower ACP engagement compared to their US-born Black and Hispanic counterparts, a gap that narrows with adjustment. We hypothesize that sociodemographic characteristics, particularly socioeconomic status, play a role in this difference as these racial disparities closed slightly after covariate adjustment for groups lower on average socioeconomic status, but widened for the group with higher on average socioeconomic status. These findings suggest immigrants may experience both systemic socioeconomic barriers and barriers specific to their cultural background that affect ability to engage in ACP. For instance, compared to other groups, immigrants from Central and South America have the lowest rates of English proficiency, which is known to affect ACP engagement.[29,30] Alternatively, Black immigrants, particularly those from Africa, are more likely to have recently immigrated to the US relative to other immigrant groups, which itself is associated with lower engagement.[31] Grouping of races and ethnicities from Asian countries with American and Alaskan Indian respondents in the “Other” category limits discussion on group-specific barriers, but similarly points to the need for further research to explore barriers for immigrants broadly, as well as for specific immigrant groups. We further hypothesize that ACP may be emphasized to a greater extent in Europe compared to Latin American and Africa, which can be explored in future studies.

Results corroborate the association between acculturation, as proxied by time spent in the US, and ACP engagement. Our results were similar in magnitude to prior data from the National Health and Aging Trends Study (NHATS), with each year spent in the US increasing odds of ACP engagement for all behaviors by roughly 3–4%. Whereas prior studies have measured acculturation with age at migration, noting that those who migrate at earlier ages may display faster rates of acculturation, this study used years spent in the US. Longer residence in the US increases exposure to behaviors, customs, and values that facilitate participation in society. To find a consistent magnitude of association while employing alternate measures of a similar concept demonstrates the significant relationship between acculturation on ACP engagement and represents a strength and contribution of this study.

Our results have clinical implications as ACP is central to respecting treatment preferences and improving preparation of older immigrant adults and their proxies for future decision-making at the end of life. Notably, there has been recent debate about the value and about the relationship between ACP and goal-concordant care. The prior use of a narrower definition of ACP focused mainly on advance directive completion contributes in part to the mixed evidence of the benefits of ACP. However, the field of ACP has evolved over the past decade to broaden its focus to include preparation for communication and medical decision making.[15,21,32] Several larger trials and studies suggest that employing this broader view of ACP may contribute to improved goal-concordant care.[33,34] Nevertheless, there is relative consensus in the field about the value and importance of ACP to decrease surrogate burden and improve satisfaction with communication, medical decision making, and medical care.[35–39] ACP may be especially relevant in helping immigrants and their families navigate

unfamiliar care patterns and norms (including higher rates of aggressive care at the end of life) as compared to their countries of origin. We hypothesize that disparities in ACP may contribute to higher rates of burdensome end-of-life care among immigrants noted in prior literature. Clinicians should recognize that social and structural determinants of health can intersect with the unique health care experiences and needs of immigrants. While interventions exist to address social and structural barriers to ACP engagement in diverse populations, future efforts should consider identifying recently immigrated communities and the unique barriers to engagement for specific groups.[40]

The current study should be interpreted in the context of several limitations. First, ACP engagement was self-reported and without external verification in a healthcare record. However, this may better reflect real-world practices since ACP discussions often do not involve physicians and are not documented. Second, the HRS has limited inclusion of immigrants who do not speak English or Spanish, the two most common languages in the US, which may limit generalizability. However, studies that investigated non-English and non-Spanish speaking racial and ethnic groups have found similar patterns of lower ACP engagement among immigrants compared to US-born counterparts.[42] Additionally, we did not adjust for the frequency of contact with the healthcare system, which may correlate with age, time spent in the US, and engagement in ACP. However, this is unlikely to explain the striking amount of time—nearly 70 years of residence in the US—for older immigrant adults to reach similar probabilities of engagement across all behaviors as their US-born counterparts, even after standardizing age and adjusting for other covariates. Lastly, confounding by geography may exist as many immigrant communities live in areas that may be systematically different with respect to ACP engagement.

In conclusion, immigrants have lower engagement in ACP than US-born older adults, particularly among those who recently immigrated. Engagement was strongly tied to self-reported race/ethnicity, where immigrants identifying as Hispanic ethnicity and Black had lower ACP engagement compared to US-born counterparts. Future studies should explore the unique barriers to ACP engagement among different immigrant populations.

## ACKNOWLEDGEMENTS

Author contributions: Conception and design: DMP, RS, IC, AS, AK; Acquisition of the data: IC, AS, AK; Analysis and interpretation: DMP, IC, AK; Drafting and revising manuscript: DMP, RS, IC, AS, AK; Approval of final manuscript: DMP, RS, IC, AS, AK

**Funding:**

Dallas Mindo-Panusis was supported by TL1 Pre-doctoral training grant. Dr. Ashwin Kotwal's effort on this project was supported by grants from the National Institute on Aging (K23AG065438), the NIA Claude D. Pepper Older Americans Independence Center (P30AG044281), the National Palliative Care Research Center Kornfield Scholar's Award, and the Hellman Foundation Award for Early-Career Faculty. Dr. Sudore is funded in part by the National Institute on Aging, National Institutes of Health (K24AG054415).

**Sponsor's Role:**

The sponsor had no role in the design, methods, data collection, analysis, or preparation of the paper.

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**Key Points:**

1. Older immigrant adults in the US had lower prevalence of advance care planning compared older adults born in the US.
2. Accounting for sociodemographic characteristics, health status, and functional disability narrows, but does not eliminate, the differences in advance care planning engagement between older immigrant adults and older US-born adults.
3. Older immigrant adults who have recently immigrated to the US have a substantially lower probability of engagement in advance care planning compared to those who have lived in the US longer.

**Why does this matter?**

Clinicians should be aware that a history of immigration and less time spent in the US are associated with lower engagement in three different advance care planning behaviors compared to those born in the US. Targeted advanced care planning engagement may help improve end-of-life decision making for older immigrant adults and their proxies in future decision making.

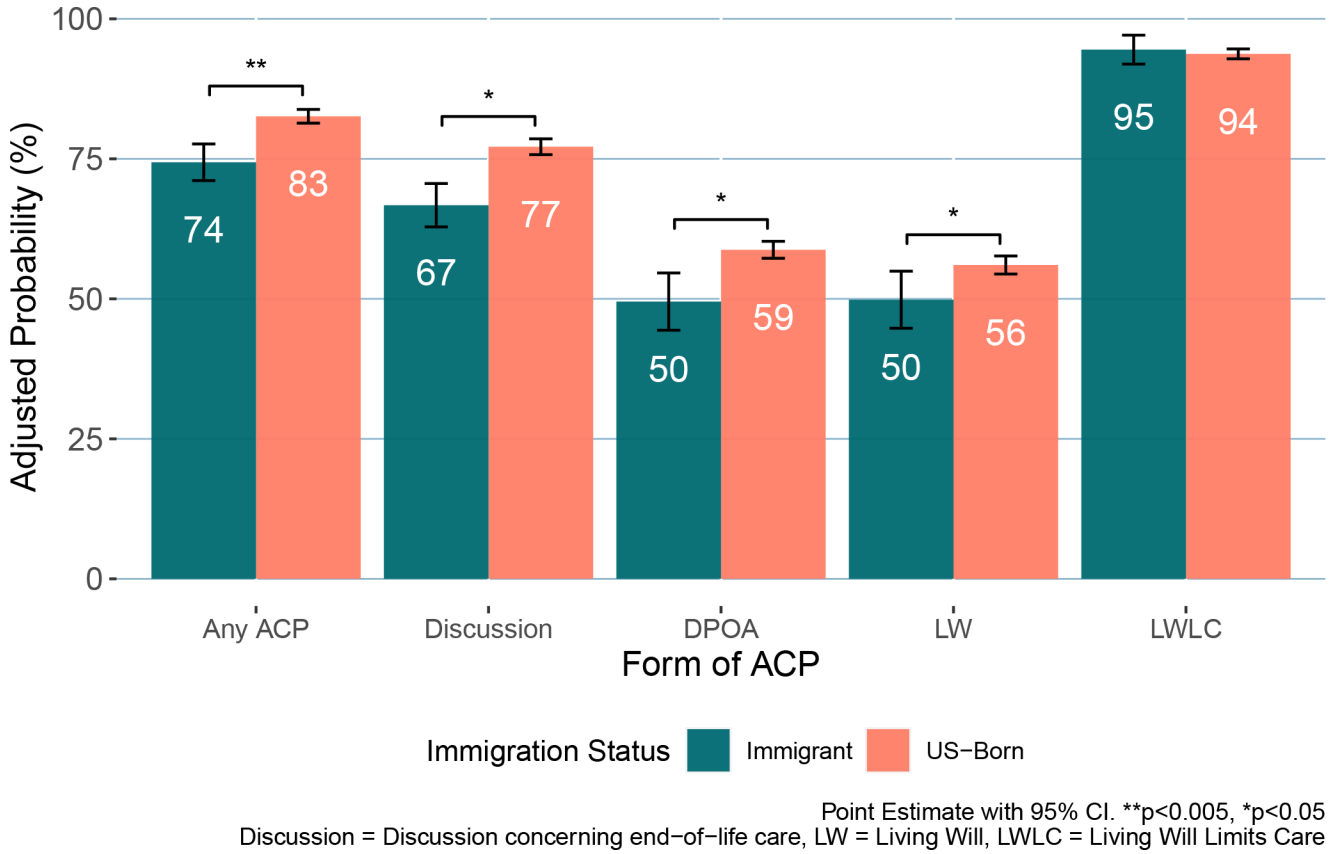


**Figure 1.**

The Adjusted Probability of Engagement in Advanced Care Planning by Immigration Status

Figure 1 displays the estimated probability of engagement (as a percentage) of 3 different advance care planning behaviors and one composite measure that captures having at least one of the three behaviors. Adjusted covariates include age, gender, race, Hispanic ethnicity, marital status, number of children at home, religiosity, education, assets, and life expectancy. Discussion = discussion concerning end-of-life care, DPOA = designated power of attorney, LW = living will.

**p<0.005, *p<0.05

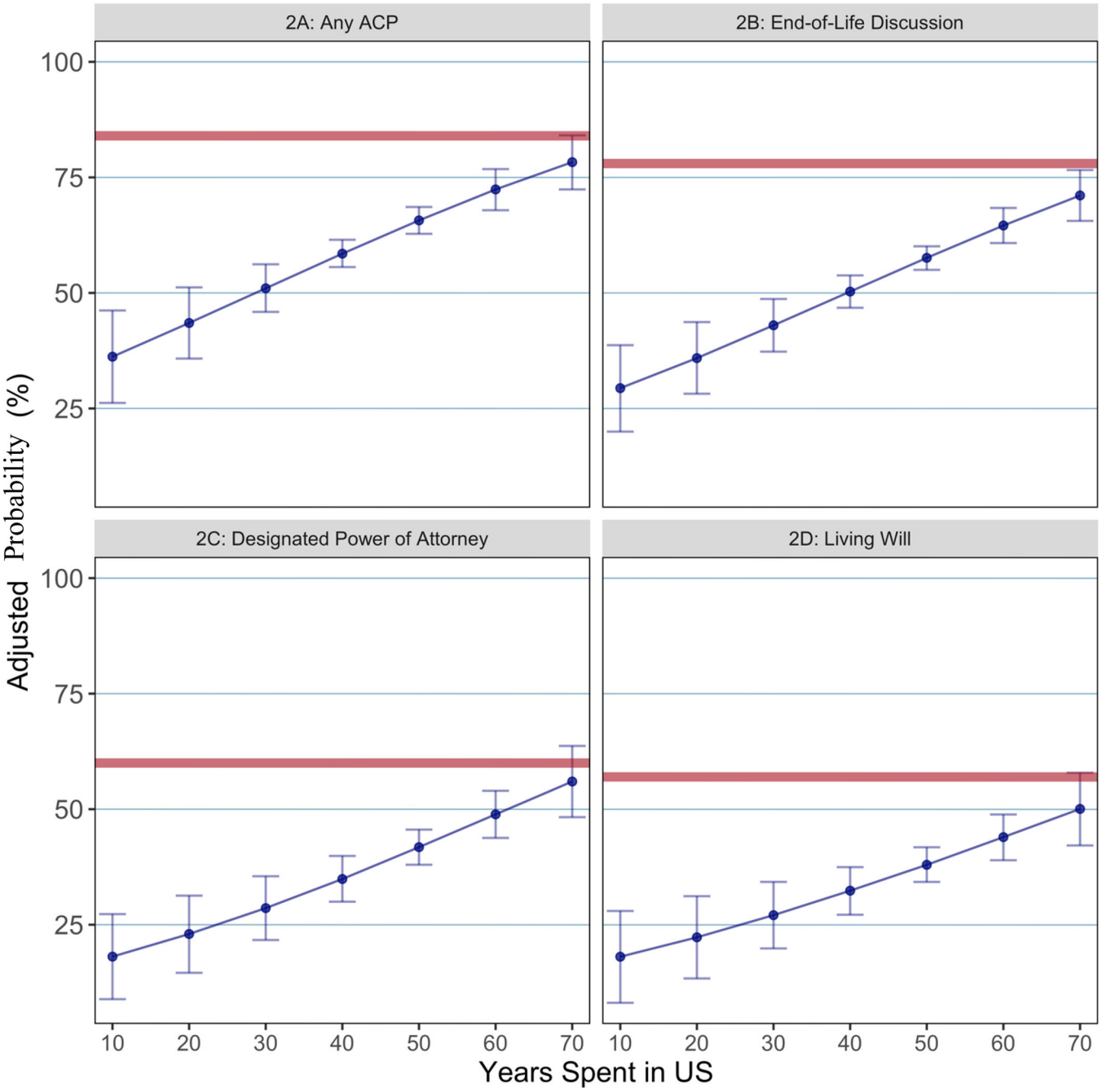


**Figure 2.**

Age-Adjusted Probability of Engagement in Advance Care Planning by Years Spent in the United States

Figure 2 displays the estimated probability of engagement (as a percentage) of 3 different advance care planning behaviors and one composite measure that captures having at least one of the three behaviors by years spent in the US among the immigrant cohort. Covariate adjustments include gender, race, Hispanic ethnicity, marital status, number of children at home, religiosity, education, assets, and life expectancy. The immigrant cohort age is

standardized to match the average probability of engagement among the US-born cohort at an average age of 74, represented by the red line. Point Estimates with 95% CI.

**Table 1.**

Sample characteristics of 2016 Health and Retirement Study (N=9928)

| Characteristics | | US-Born N (Survey Weighted %) | Immigrant N (Survey Weighted %) | p-value |
|---|---|---|---|---|
| **Characteristics** | | 8751 (90%) | 1177 (10%) | |
| Age, median (IQR)† | | 75 (69–81) | 75 (68–80) | 0.02 |
| Gender‡ | Female | 5217 (55%) | 688 (58%) | 0.09 |
| Race/Ethnicity‡ | White | 6656 (85%) | 297 (35%) | <0.001 |
| | Black | 1504 (9%) | 139 (8%) | |
| | Hispanic | 448 (4%) | 624 (45%) | |
| | Other | 141 (2%) | 114 (12%) | |
| Education‡ | < Bachelors | 4563 (46%) | 801 (63%) | <0.001 |
| | ≥ Bachelors | 4187 (54%) | 375 (37%) | |
| Assets ($)‡ | <6000 | 1246 (11%) | 338 (24%) | <0.001 |
| | 6,000–80,999 | 1544 (15%) | 253 (20%) | |
| | 81,000–238,999 | 1982 (22%) | 209 (16%) | |
| | ≥239,000 | 3979 (52%) | 377 (40%) | |
| Marital Status‡ | Not married | 1414 (18%) | 164 (15%) | 0.09 |
| | Married | 4646 (59%) | 700 (61%) | |
| | Widowed | 2678 (23%) | 311 (25%) | |
| Number Children at Home‡ | 0 | 7126 (84%) | 773 (71%) | <0.001 |
| | 1 | 1431 (14%) | 313 (22%) | |
| | 2–10 | 194 (2%) | 91 (7%) | |
| Religion Service Attendance Frequency‡ | Not at all | 2412 (30%) | 286 (28%) | 0.02 |
| | > 1 / week | 1287 (13%) | 155 (12%) | |
| | 1 / week | 2476 (27%) | 329 (25%) | |
| | 2–3 / month | 977 (11%) | 162 (15%) | |
| | 1+ / year | 1541 (19%) | 226 (20%) | |
| 4-year Mortality Risk‡ | 4% | 695 (10%) | 115 (9%) | 0.86 |
| | 15% | 3223 (42%) | 473 (44%) | |
| | 40% | 3428 (36%) | 419 (34%) | |
| | 67% | 1405 (12%) | 170 (13%) | |
| Years in the US, median (IQR) | | | 47 (9–56) | |
| Age Arrived in the US, median (IQR) | | | 28 (21–38) | |

†Adjusted Wald Test

$^{\neq}$Pearson chi-squared

4-year mortality risk is determined by the Lee Prognostic Index.

Percentages in the table are column percentages; percentages shown in the table are adjusted for survey weights and thus may not correspond directly to the unadjusted N listed in each cell.

**Table 2.**

Comparison of Advance Care Planning Behavior by Immigrant Status, stratified by Race and Hispanic Ethnicity

| | Race & Hispanic Ethnicity | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | ***Black*** | | ***Hispanic*** | | ***Other*** | | ***White*** | | **Total** | |
| | *USB* | *IMG* | *USB* | *IMG* | *USB* | *IMG* | *USB* | *IMG* | *USB* | *IMG* |
| **Any ACP** | 70% | 52% | 66% | 49% | 69% | 64% | 86% | 85% | 84% | 63% |
| aOR [95% CI] | 0.47 [0.32,0.68] | | 0.50 [0.35,0.72] | | 0.65 [0.25,1.69] | | 0.69 [0.46,1.02] | | 0.58 [0.46,0.72] | |
| **Discuss EOL** | 62% | 44% | 62% | 40% | 64% | 58% | 81% | 78% | 78% | 56% |
| aOR [95% CI] | 0.47 [0.29,0.78] | | 0.38 [0.27,0.53] | | 0.58 [0.23,1.48] | | 0.73 [0.50,1.06] | | 0.56 [0.45,0.70] | |
| **DPOA** | 43% | 30% | 42% | 28% | 47% | 42% | 63% | 61% | 60% | 42% |
| aOR [95% CI] | 0.59 [0.29,1.22] | | 0.56 [0.37,0.82] | | 0.66 [0.34,1.31] | | 0.73 [0.53,1.00] | | 0.65 [0.52,0.83] | |
| **Living Will** | 35% | 24% | 32% | 22% | 38% | 41% | 61% | 61% | 57% | 38% |
| aOR [95% CI] | 0.67 [0.34,1.33] | | 0.62 [0.38,1.00] | | 0.93 [0.44,1.98] | | 0.81 [0.61,1.09] | | 0.76 [0.59,0.96] | |
| **LWLC** | 84% | 100% | 96% | 93% | 85% | 83% | 94% | 96% | 94% | 93% |
| aOR [95% CI] | *NA*[*] | | 0.54 [0.13,2.22] | | 0.94 [0.16,5.48] | | 1.32 [0.56,3.11] | | 1.16 [0.69,1.93] | |

USB = US-born, IMG = immigrant, ACP = advance care planning, EOL = end-of-life, DPOA = designated power of attorney, LWLC = living will limits care, aOR = adjusted odds ratio

Percentages represent the unadjusted frequency of engaging in each ACP behavior.

Adjusted Odds ratios were estimated using multivariate logistic regression adjusting for age, gender, marital status, number of children at home, religiosity, education, assets, and life expectancy.

[*]All self-identifying Black immigrant respondents that reported having a living will also reported that the living will limited care.