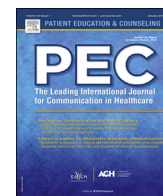




Contents lists available at ScienceDirect

## Patient Education and Counseling

journal homepage: [www.elsevier.com/locate/pateducou](http://www.elsevier.com/locate/pateducou)



# Individual, interpersonal, and health care factors associated with informal and formal advance care planning in a nationally-representative sample of midlife and older adults

Daniel Siconolfi<sup>a,\*</sup>, Julia Bandini<sup>b</sup>, Emily Chen<sup>c</sup>

<sup>a</sup> RAND Corporation, 4570 Fifth Ave, Suite 600, Pittsburgh, PA, 15213, USA

<sup>b</sup> RAND Corporation, 20 Park Plaza, Suite 920, Boston, MA, 02116, USA

<sup>c</sup> RAND Corporation, 1200 South Hayes St, Arlington, VA, 22202, USA

### ARTICLE INFO

#### Article history:

Received 3 September 2020

Received in revised form 30 November 2020

Accepted 23 December 2020

#### Keywords:

Aging  
Advance directives  
Advance care planning  
Decision making  
Proxy

### ABSTRACT

**Objective:** Assess correlates of advance care planning (ACP) among midlife and older adults in the United States, with attention to informal planning (e.g., conversations) and formal planning (e.g., legal documentation such as a living will).

**Methods:** Data were collected from a nationally-representative U.S. sample of adults ages 55–74.

**Results:** Informal ACP was positively associated with greater confidence, history of life-threatening illness, designation as health care decision maker for someone else, knowing at least one negative end-of-life (EOL) story in one's personal network, a desire to ease surrogates' decision making, and having a health care provider who had broached ACP. Formal ACP was positively associated with greater confidence, designation as a health care decision maker, having a provider who had broached ACP, and primarily receiving medical care from a doctor's office, and marginally negatively associated with health worry.

**Conclusions:** There are relevant correlates of advance care planning at the individual, interpersonal, and health care levels, with implications for increasing uptake of ACP.

**Practice implications:** A desire to mitigate proxies' decision-making burden was a significant motivator for ACP conversations. Awareness of negative EOL experiences may also motivate these conversations. Health care providers have a powerful role in formal and informal ACP uptake.

© 2021 Elsevier B.V. All rights reserved.

## 1. Introduction

At the end of life or during serious illness, many adults receive unwanted care in institutional settings, including medical interventions that are life-prolonging and potentially painful [1]. Advance care planning (ACP) permits patients to communicate and document their preferences should they become unable to make medical care decisions due to physical, cognitive, and/or communicative impairments. ACP has potential benefits for patients, kin and families, and the health care system. First, ACP can increase the concordance between persons' wishes and care they receive and can increase the provision of hospice and palliative care [2–6]. Second, ACP may also improve outcomes for next of kin by reducing the burden and distress associated with decision-making because these preferences were communicated in advance [4,7–9].

Further, ACP is likely to reduce expenditures given the high costs of care at the end-of-life in hospital and ICU settings, often for care that individuals may not desire [1,10–13].

Despite these potential benefits, ACP is underutilized in the United States. Between half to more than two-thirds of older adults are unable to make or communicate decisions at the end of life [1]. Among adults ages 75 and older, more than 1 in 4 have not considered or documented their preferences for care at the end of life [1]. ACP completion is even lower among younger adults, such as those in midlife and approaching older adulthood (e.g., ages 55–74) [14,15].

ACP includes both formal and informal dimensions, each of which are important [16,17]. Formal ACP includes legal documents, such as advance directives, living wills, and durable power of attorney for health care (DPOAHC). Informal ACP entails “values focused discussions” [18] that help proxy decision makers and physicians identify the types of care the recipient would desire. Informal ACP is critical, regardless of formal ACP completion. These conversations may help surrogates make decisions that align with

\* Corresponding author.

E-mail addresses: [dsiconol@rand.org](mailto:dsiconol@rand.org) (D. Siconolfi), [jbandini@rand.org](mailto:jbandini@rand.org) (J. Bandini), [echen@rand.org](mailto:echen@rand.org) (E. Chen).

<https://doi.org/10.1016/j.pec.2020.12.023>

0738-3991/© 2021 Elsevier B.V. All rights reserved.

the patient's values, given that end of life scenarios are often unpredictable and can be complicated by factors such as family conflict in decision making [19–23].

To date, research has primarily focused on sociodemographic differences in ACP, with the literature leaning toward greater attention to formal ACP. For example, there are well-documented disparities in ACP in the general population, particularly with regard to race and ethnicity, socioeconomic status, and educational attainment [24–29]. There has also been less attention to the informal dimension of ACP, relative to formal ACP. Less is known regarding other factors, such as psychosocial factors, as potential correlates of ACP [30]. Research has also focused on a relatively narrow population of older adults and persons with serious illness. Much less is known regarding the potential barriers or facilitators for conversations or formal documentation among “young-old” adults (i.e., ages 55–74) in the general U.S. population.

To address these gaps in knowledge regarding the prevalence and correlates of informal and formal ACP among contemporary midlife and older adults, we collected data from a nationally-representative U.S. panel. The potential correlates we examined span factors at the individual, interpersonal, and health care levels. We hypothesized these factors to be relevant to ACP, based on a review of the literature and our own preliminary qualitative research.

## 2. Methods

### 2.1. Data sources

Data were collected from the American Life Panel (ALP), an ongoing panel study of about 6000 adults, weighted to be representative of the U.S. population. The ALP is described in detail elsewhere [31]. We distributed this survey to the subsample of ALP participants ages 55–74 between September and October 2019 ( $n = 1678$  members). Panelists received weekly survey reminders. The effort yielded 1297 completes (77% response rate) with 12 incompletes (<1%). All data were self-reported via the internet panel. Surveys took approximately 15 min to complete and respondents received \$10 remuneration. The study was reviewed by RAND's institutional review board.

We developed the survey based on formative qualitative research and literature reviews [32]. Formative qualitative research included in-depth 1:1 interviews ( $n = 38$ ) with midlife and older adults ages 55–74, including those who had and had not engaged in informal or formal ACP [33]. For this analysis, we conceptually grouped independent variables at the individual, interpersonal, and health care levels.

### 2.2. Dependent variables

The two ACP outcomes were each analyzed as a binary lifetime variable. Informal ACP was measured with a single item (“We would like to ask you some questions about healthcare decisions that might need to be made for you in the future if you are unable to make them yourself. People sometimes make plans about the types of care or medical treatment they would want or not want, if they were to become seriously ill. Have you ever discussed with anyone the care or medical treatment you would want to receive if you were to become seriously ill in the future?”).

Formal ACP was defined as completing an advance directive, living will, or a durable power of attorney for health care (DPOAHC). In addition to mentioning each document by name, the respective questions described the documents. Advance directives and living wills were described as “written instructions about the care or medical treatment that you want to receive if you

can not make those decisions yourself.” DPOAHC was described as “legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you can not make those decisions yourself.”

### 2.3. Independent variables

#### 2.3.1. Individual level independent variables

Self-rated health was assessed using a standard response set (excellent; very good; good; fair; poor). Experience with life-threatening illnesses (“cancer, organ failure, or an illness that without treatment is likely to cause death”) was assessed using a multiple choice item that included one's own illness history (“myself”) as well as immediate family members' illness histories. A similar item assessed personal employment in a medical occupation (myself; family member). Responses indicating “myself” for either of these two items were used as the individual-level variables, respectively.

The individual level also included three attitudinal variables and three ACP motivations. Confidence in ACP skills (“When you think about planning for health care decisions and decision makers in case you become seriously ill, to what extent do you feel confident?”) was assessed with five-point Likert ranging from “Not at all” to “extremely.” Health worry was assessed using an item from the Whiteley Index [34] (“I worry a lot about my health”), and was coded as a binary variable for analysis where “agree” or greater on the 5-point Likert indicated health worry. Death avoidance was analyzed as a binary variable where persons who agreed “moderately” or greater with a single item (“Whenever the thought of death enters my mind, I try to push it away”) [35] were coded as death avoidant.

Finally, three individual-level motivations for informal ACP were measured within a larger question matrix assessing five potential motivations (two of which were interpersonal, described later). The three individual-level items included religious or spiritual reasons (“to ensure that the medical care I receive aligns with my religious or spiritual values”), a desire to reduce suffering at the end of life (verbatim), and a desire for end-of-life (EOL) care concordant with preferences (“to ensure that my wishes inform the care I receive”). The question text was tailored based on a respondent's prior response to the informal ACP item, such that persons who had engaged in informal ACP were asked “What are your reasons for talking about your health care wishes with someone in your life?” and those without informal ACP were asked, “Which of these reasons would motivate you . . . ?”.

#### 2.3.2. Interpersonal level independent variables

Family members' history of life-threatening illness and family members' employment in medical occupations were derived from the respective items described above at the Individual level (see 2.3.1). Satisfaction with one's personal relationships was assessed with an item from the World Health Organization's Quality of Life BREF survey [36]. The five-point Likert response was recoded as “satisfied or greater” for analysis.

We also measured the extent to which other people's discomfort was a barrier to informal ACP in two steps. First, respondents were asked “how unwilling or reluctant” their ideal ACP conversation partners were. Second, respondents who indicated anything greater than “not at all” were asked how much this unwillingness or reluctance “affected your ability to have these conversations with them?”. A response of “somewhat” or greater was coded as a barrier. Respondents who indicated “not at all” to the first question were coded as “no barrier.”

The interpersonal level also included the two remaining motivations from the ACP motivations matrix: a desire to “make

decisions easier for my family/decision maker," and a desire to "preserve financial assets or avoid spending money on unwanted medical care." We grouped the financial motivation at the interpersonal level because formative interview participants had expressed desires to preserve assets for their estate and next of kin.

We assessed respondent's exposure to four negative EOL scenarios, derived from common themes in the formative interviews. We asked respondents whether they knew someone in their personal network who: 1) had to make medical decisions for someone else at EOL, without being sure of what that person really wanted 2) experienced strain or conflict with family members when these decisions were made, 3) received EOL care that the respondent felt "was too extreme, even if it's what that [dying] person may have wanted," or 4) received EOL care that the respondent believed was incongruent with the dying person's own wishes. Based on frequencies, we combined these four items into a binary variable indicating one or more of these experiences, versus none. Finally, we included two items indicating whether the respondent themselves had been appointed, and/or served as someone else's medical decision maker.

### 2.3.3. Health care level independent variables

We assessed whether a health care provider had ever brought up ACP. We also asked respondents for their usual source of medical care (doctor's office or health center; walk-in clinics including urgent care and retail clinics; telemedicine; emergency departments; none; other). Based on frequency data, we created a binary variable indicating a doctor's office/health center as the usual source of care, versus elsewhere.

### 2.3.4. Demographic control variables

Race and ethnicity were combined into a single variable (White non-Hispanic; Black non-Hispanic; Other non-Hispanic; and Hispanic). Gender was assessed as male or female. We stratified age as midlife (55–64) versus older adults (65–74) because age 65 is a traditional age of eligibility for retirement benefits, including social security insurance and Medicare. Marital status was categorized as currently married/partnered, divorced/separated, widowed, or single and never married. Employment status was collapsed into categories reflecting currently employed, disabled, retired, or other (unemployed and looking for work; temporarily laid off/on sick leave/other leave; homemaker; other). Finally, educational attainment was coded as Bachelor's degree or more, versus less than a Bachelor's degree.

## 2.4. Analysis plan

The data were weighted to permit nationally-representative estimates; weighting is described in detail elsewhere [31]. Analyses were completed using Stata 16 [37], supplemented with the *fitstat* package [38]. Each dependent variable (informal ACP, formal ACP) was examined separately as an outcome. We used bivariate logistic regression to produce unadjusted odds ratios between each independent variable and the given ACP behavior. We then created a multivariable logistic regression model where all independent variables were entered simultaneously, in order to adjust for each other. This produced adjusted odds ratios for each covariate of interest, indicating the association with the given ACP behavior after accounting for the other variables. Variables were checked for multicollinearity and all VIFs were acceptable ( $< 2.0$ ). Results were considered statistically significant at  $p < 0.05$ . Model fit was assessed using design-based goodness-of-fit for survey logistic regression and McFadden's adjusted pseudo- $R^2$  [39,40]. We used McFadden's adjusted  $R^2$  to conservatively assess model fit because it penalizes the  $R^2$  for the number of independent variables, which otherwise inflate  $R^2$ .

## 3. Results

The weighted sample is described in detail in Table 1. The majority of the adults were non-Hispanic White (70%). Most adults were currently married or partnered (66%). About half were still in the workforce, and about one-third had retired. The majority of adults (47%) reported "very good" or "excellent" health. Nine percent had ever had a life-threatening illness.

**Table 1**

Weighted sample descriptives; advance care planning among midlife and older adults.

Characteristic	Percent
<b>Outcomes</b>	
Formal ACP (Power of Attorney and/or Advance Directive)	44.50%
Durable Power of Attorney for Health Care	39.03%
Advance Directive or Living Will	37.38%
Informal ACP (ever had conversations regarding care preferences for serious illness or EOL)	64.63%
Either informal and/or formal ACP	70.00%
<b>Demographics</b>	
Race and ethnicity	
White non-Hispanic	70.04%
Black non-Hispanic	9.29%
Other non-Hispanic	4.11%
Hispanic	16.56%
Female (versus Male)	52.71%
Ages 55–64 (versus 65–74)	58.75%
Marital status	
Married/partnered	65.80%
Divorced/separated	19.85%
Widowed	5.92%
Single and never married	8.44%
Employment	
Currently working	44.94%
Disabled	10.48%
Retired	36.87%
Unemployed, other	7.71%
Bachelor's degree or more	32.62%
<b>Individual factors</b>	
Medical occupation - self	9.80%
Confidence in ACP	
Not at all confident	6.30%
A little confident	17.92%
Somewhat confident	40.47%
Very confident	29.07%
Extremely confident	6.23%
Worry about health	23.97%
Self-rated health	
Poor	3.95%
Fair	14.47%
Good	34.27%
Very good	39.22%
Excellent	8.09%
Death avoidance (push away thoughts about death)	37.56%
Life threatening Illness - Self	9.15%
Motivation for ACP - EOL care concordant with preferences	62.93%
Motivation for ACP - Religious or spiritual reasons	19.74%
Motivation for ACP - Reduce suffering at EOL	54.99%
<b>Interpersonal factors</b>	
Medical occupation - family	30.11%
Satisfied with personal relationships	73.25%
Other persons' discomfort is a barrier to ACP conversations	23.57%
Life threatening Illness - Family member	56.44%
Designated as health care decision-maker for someone else	33.26%
Served as medical decision maker for someone else	35.63%
One or more negative EOL stories in personal network	50.43%
Motivation for ACP - Ease decision making for others at EOL	85.21%
Motivation for ACP - Reduce financial costs at EOL	44.06%
<b>Health care factors</b>	
Health care provider ever brought up ACP	28.17%
Usual source of care - Provider's office/clinic	92.61%

Among midlife and older adults, 45% had engaged in formal advance care planning; 39% had completed a DPOAHC and 37% had completed an advance directive. About two-thirds of adults (65%) had ever engaged in informal advance care planning. About 70% had engaged in either or both dimensions of ACP (informal and/or formal). Most adults (76%) were at least "somewhat confident" or greater in their advance care planning abilities. For hypothetical or realized ACP motivations at the individual level, the most commonly-endorsed motivation was a desire to receive EOL care concordant with preferences (63%), followed by a desire to reduce suffering at the end of life (55%), and much less commonly, a desire to ensure care concordant with religious or spiritual preferences (20%).

About half of adults had a family member who had experienced a life-threatening illness (56%), and half reported at least one negative EOL story in their personal network (50%). About one-third each had been designated as a health care decision maker for someone else, and had served as a medical decision maker for someone else at the end of life (33% and 36%). One-fourth of adults reported that others' reluctance or discomfort with EOL topics was a "somewhat" or greater barrier to these conversations (24%). For ACP motivations at the interpersonal level, a desire to ease decision-making for others was substantially more common than a desire to reduce financial costs at the end of life (85% versus 44%). About one-quarter of adults reported that their health care provider had ever broached ACP (28%).

### 3.1. Informal advance care planning

The bivariate (unadjusted) and multivariable (adjusted) models are shown in Table 2. In the unadjusted tests, many of the covariates had statistically significant associations with informal ACP conversations. In the multivariable model for informal ACP, we adjusted for all variables simultaneously, including sociodemographics. McFadden's adjusted  $R^2$  was 0.24, indicating very good model fit [39,40]. At the individual level, greater confidence in ACP (OR = 2.02) and a lifetime history of life-threatening illness (OR =

2.11) were both positively associated with informal ACP. At the interpersonal level, designation as a healthcare decision-maker for someone else (OR = 2.97), having at least one negative EOL story in one's personal network (OR = 2.05), and a motivation to ease decision making for next of kin (OR = 2.11) were all positively associated with informal ACP. For health care factors, having a provider who had ever brought up ACP was associated with informal ACP (OR = 2.72).

### 3.2. Formal advance care planning

The bivariate and multivariable models are shown in Table 3. Similar to our findings for informal ACP, many of the covariates were significantly associated with formal ACP in bivariate tests. In the multivariable model for formal ACP, we adjusted for all variables simultaneously, including sociodemographics. McFadden's adjusted  $R^2$  was 0.24, indicating very good model fit. At the individual level, greater confidence in ACP (OR = 1.80) was positively associated with formal ACP, and health worry was marginally negatively associated with formal ACP (OR = 0.63). At the interpersonal level, having been designated as a health care decision maker for someone else was positively associated with the respondent having engaged in formal ACP (OR = 5.31). Finally, both health care factors were positively associated with formal ACP: having a provider who had brought up ACP (OR = 1.98), and typically receiving care from a doctor's office (OR = 2.07).

### 3.3. Evidence of ACP disparities

Finally, although we included sociodemographics primarily as control variables (point estimates not shown in tables), we note that non-Hispanic Black adults had lower odds of informal ACP (OR = 0.44, 95% CI = 0.22, 0.88;  $p = .02$ ) and formal ACP (OR = 0.38, 95% CI = 0.18, 0.81;  $p = .01$ ) compared to white non-Hispanic adults, even after adjusting for all of the individual, interpersonal, and health care variables.

**Table 2**  
Barriers and facilitators for informal advance care planning among midlife and older adults.

	Unadjusted			Adjusted (Adj. $R^2 = 0.24$ )		
	uOR	p	95% CI	aOR	p	95% CI
<b>Individual factors</b>						
Confidence in ACP	2.11*	<0.001	1.70, 2.61	2.02*	<0.001	1.64, 2.49
Worry about health	1.01	0.915	0.87, 1.17	1.31	0.271	0.81, 2.12
Self-rated health	1.11	0.235	0.94, 1.31	1.12	0.430	0.85, 1.48
Push away thoughts about death	0.58*	0.002	0.41, 0.83	0.72	0.094	0.49, 1.06
Life threatening illness - self	2.62*	0.001	1.48, 4.64	2.11*	0.028	1.08, 4.12
Medical occupation - self	1.04	0.908	0.51, 2.14	0.97	0.917	0.54, 1.73
ACP motivation - Religious or spiritual reasons	1.15	0.504	0.77, 1.71	0.94	0.803	0.59, 1.50
ACP motivation - Reduce suffering at EOL	1.26	0.184	0.90, 1.76	1.08	0.724	0.70, 1.65
ACP motivation - EOL care concordant with preferences	1.79*	0.001	1.27, 2.54	1.25	0.281	0.83, 1.88
<b>Interpersonal factors</b>						
Satisfied with personal relationships	1.25*	0.007	1.06, 1.48	1.32	0.195	0.87, 1.99
Other persons' discomfort impedes ACP conversations	0.66*	0.045	0.44, 0.99	0.75	0.198	0.48, 1.16
Life threatening illness - Family member	1.39	0.057	0.99, 1.96	0.93	0.719	0.62, 1.39
Medical occupation - family	1.44	0.051	1.00, 2.09	1.19	0.429	0.77, 1.83
Designated as health care decision-maker for someone else	4.97*	<0.001	3.41, 7.26	2.97*	<0.001	1.89, 4.67
Served as medical decision maker for someone else	2.27*	<0.001	1.60, 3.22	1.23	0.365	0.79, 1.91
One or more negative EOL stories in personal network	2.69*	<0.001	1.93, 3.73	2.05*	<0.001	1.39, 3.03
ACP motivation - Ease EOL decision making for others	3.03*	<0.001	1.87, 4.91	2.11*	0.002	1.31, 3.39
ACP motivation - Reduce financial costs at EOL	1.12	0.488	0.81, 1.57	0.67	0.067	0.43, 1.03
<b>Health care factors</b>						
Provider brought up ACP	3.79*	<0.001	2.47, 5.80	2.72*	<0.001	1.65, 4.48
Usual source of care - Provider's office/clinic	1.96*	0.022	1.10, 3.49	1.39	0.306	0.74, 2.62

\*  $p < .05$ . Models control for race/ethnicity, age group, gender, marital status, employment status, and educational attainment. Adjusted  $R^2$  is McFadden's Adjusted  $R^2$ .

**Table 3**  
Barriers and facilitators for formal advance care planning among midlife and older adults.

	Unadjusted			Adjusted (Adj. R <sup>2</sup> = 0.24)		
	uOR	p	95% CI	aOR	p	95% CI
<b>Individual factors</b>						
Confidence in ACP	1.99*	<0.001	1.60, 2.48	1.80*	<0.001	1.49, 2.18
Worry about health	1.00	0.968	0.86, 1.16	0.63	0.051	0.40, 1.00
Self-rated health	1.05	0.564	0.89, 1.24	0.91	0.439	0.72, 1.15
Push away thoughts about death	0.67*	0.021	0.48, 0.94	0.94	0.757	0.63, 1.39
Life threatening illness - self	1.80*	0.018	1.11, 2.91	1.19	0.531	0.69, 2.05
Medical occupation - self	1.00	0.995	0.57, 1.74	1.05	0.872	0.58, 1.92
ACP motivation - Religious or spiritual reasons	1.65*	0.008	1.14, 2.38	1.25	0.365	0.77, 2.03
ACP motivation - Reduce suffering at EOL	1.84*	<0.001	1.34, 2.51	1.32	0.174	0.88, 1.99
ACP motivation - EOL care concordant with preferences	2.28*	<0.001	1.64, 3.18	1.28	0.234	0.85, 1.92
<b>Interpersonal factors</b>						
Satisfied with personal relationships	1.14	0.077	0.99, 1.33	1.14	0.544	0.75, 1.73
Other persons' discomfort impedes ACP conversations	0.73	0.133	0.49, 1.10	1.04	0.861	0.67, 1.62
Life threatening illness - Family member	1.24	0.199	0.89, 1.71	0.79	0.222	0.53, 1.16
Medical occupation - family	1.60*	0.008	1.13, 2.26	1.30	0.217	0.86, 1.96
Designated as health care decision-maker for someone else	6.92*	<0.001	4.85, 9.86	5.31*	<0.001	3.50, 8.06
Served as medical decision maker for someone else	1.70*	0.001	1.24, 2.35	1.03	0.877	0.69, 1.55
One or more EOL stories in personal network	1.77*	<0.001	1.30, 2.42	1.31	0.148	0.91, 1.88
ACP motivation - Ease EOL decision making for others	2.54*	<0.001	1.60, 4.02	1.48	0.144	0.87, 2.51
ACP motivation - Reduce financial costs at EOL	1.85*	<0.001	1.35, 2.53	1.23	0.332	0.81, 1.88
<b>Health care factors</b>						
Provider brought up ACP	3.24*	<0.001	2.31, 4.55	1.98*	0.006	1.22, 3.22
Usual source of care - Provider's office/clinic	2.33*	0.003	1.34, 4.07	2.07*	0.033	1.06, 4.04

\*p < .05. Models controlled for race/ethnicity, age group, gender, marital status, employment status, and educational attainment. Adjusted R<sup>2</sup> is McFadden's Adjusted R<sup>2</sup>.

## 4. Discussion and conclusions

### 4.1. Discussion

Informal ACP was more common than formal ACP among contemporary midlife and older adults ages 55–74 in the U.S., with about two-thirds of adults having had these conversations. This prevalence is comparable to that found in a recent representative survey of adults in one U.S. state [28]. Fewer than half of adults had completed formal ACP. The prevalence of formal ACP in this sample is slightly higher than rates estimated in a systematic review of advance directive prevalence (about one-third of U.S. adults), including when stratified by those with and without chronic illness [14]. However, we combined both forms of formal ACP into a single indicator, which likely contributes to the higher prevalence in our sample. When comparing our prevalence of advance directives or living wills to that found in Yadav et al. [14], the rates are more similar.

In the bivariate analyses, many of the covariates were statistically significant. Our selection of these covariates was guided by literature reviews and formative qualitative research, which may explain the large number of unadjusted, statistically significant associations. More importantly, we used multivariable models to simultaneously adjust for all covariates, including sociodemographics. These latter findings shed light on the most salient factors to address in future research and intervention development.

Most adults were at least “somewhat” confident in their skills related to ACP, and confidence was associated with both informal and formal ACP. Conversely, health worry was also associated with a marginally lower odds of having completed formal ACP. Though health worry was assessed as a global attitude in this study, it may overlap with lower self-efficacy or perceived locus of control in matters of health care planning. While interventions should engender confidence and self-efficacy, these outputs alone may not translate into increased ACP. It also possible that having

engaged in ACP engendered greater confidence; the cross-sectional nature of our data precludes an assessment of temporality.

Respondents endorsed a range of potential motivations for advance care planning. The most common motivation for ACP, a desire to ease decision-making for others, was associated with engaging in informal ACP. However, this motivation was not associated with completing formal ACP. One potential explanation is that the motivation to reduce the burden of decision-making for others is strong enough to promote conversations (a lower bar to entry) but perhaps not strong enough to promote formal planning (a much higher bar to entry). On one hand, the value of these conversations should not be discounted, as they have potential benefits for decision makers as well as the care recipient [20,21,23,41,42]. These conversations may reduce conflict and increase concordance with wishes, particularly when serious illness or the end of life are sudden or unanticipated. On the other hand, the utility of these conversations may be limited by a number of factors. First, potential challenges faced by proxy decision makers include difficulties understanding and evaluating medical information in the moment as communicated by health care providers, who themselves are often operating in a fragmented health care ecosystem [21]. Second, for informal planning with health care professionals, these conversations may not be adequately documented in electronic health records, or the documentation may not accurately reflect patients' positions [43]. The timing of these conversations, if “too early” or “too late” – what Billings et al. [44] referred to as the “Goldilocks Phenomenon” – can also limit the utility of the conversations. Finally, the quality of these conversations is also an important consideration [19,45].

Having been designated as a health care decision-maker for someone else was associated with both informal and formal ACP, and these effect sizes were the largest of all covariates. These associations likely represent reciprocity of ACP behaviors undertaken together in a dyad (e.g., marriage). However, formal ACP in dyads may not always be reciprocal. For example, Koss et al. [46]

found that one quarter of couples were a dyad in which only one person had completed an AD.

Half of adults knew at least one negative EOL story from their personal network, such as family conflict over EOL decision making. In turn, these adults were more likely to have engaged in informal ACP. Our cross-sectional survey cannot assess temporality. Thus, at least two potential explanations are possible. First, second, there may be recall bias where persons who have had these conversations are more likely to remember these stories (a measurement effect). Second, exposure to these stories may have prompted respondents to engage in conversations with others about their own care preferences (a triggering effect) [47,48].

The null finding regarding other persons' discomfort with ACP as a potential barrier to informal or formal ACP is surprising, given the range of challenging experiences that participants described in our formative qualitative interviews, and the broader research regarding the reluctance and difficulty in discussing death and dying with loved ones and providers [47,49]. This perception may reflect the "cold light of day" of the survey, which asked respondents for their global assessment rather than specific episodes. This null finding may also indicate distinct social attitudes among the baby boomer cohort. Their peers may be more receptive to these conversations, and/or baby boomers may be more willing than earlier cohorts to pursue ACP conversations with reluctant conversation partners.

Our findings also indicate health care providers' critical role in promoting ACP among this cohort. Having a provider who brought up ACP was associated with both informal and formal ACP, and the effect size was larger than most other variables. It is plausible that persons who have engaged in ACP are more likely to recall a provider's suggestion for ACP. Nevertheless, other research supports the instrumental role of providers in increasing ACP uptake [47].

Finally, we note the striking racial disparity in both informal and formal ACP among Black adults compared to White adults. Our study adds weight to the existing evidence for this disparity [26,28,50] because we further adjusted for a range of individual, interpersonal, and health care factors that might explain differences in ACP across the two racial groups. This suggests that there are other underlying explanations for these racial disparities that were not captured in our survey, and are important areas for future research.

We note several limitations and strengths of this study. First, data were drawn from an ongoing panel study of adults, weighted to be representative of the U.S. general population. Strengths of our study include the use of formative research with the target population to develop the survey instrument and the use of a nationally-representative sample of midlife and older adults. However, there are potential biases in panel surveys including conditioning and attrition [51,52]. Additionally, the survey was only administered in English. All data were self-reported and subject to social desirability bias. There are also other relevant factors not included in this survey which might further explain differences in ACP prevalence, such as medical mistrust [29]. Still, our models demonstrated very good fit for the data, even after accounting for the large number of variables in the models. Finally, we did not assess the quality of informal ACP conversations. One theory-based approach for quality assessment in future studies, as implemented by Van Scoy et al. [53], is the extent to which these conversations achieve patients' task goals (e.g., establishing a decision), relational goals (e.g., interpersonal closeness), and identity goals (e.g., preserving personhood) [45,53,54]. Future research could explore the extent to which the multilevel factors we examined are associated with aspects of conversation quality.

## 4.2. Conclusion

The COVID-19 pandemic is changing views of vulnerability and mortality risk and the context for critical illness care among the general population [55–58]. This work also provides a benchmark against which future, post-pandemic investigations can be compared to aid understanding of changes in ACP prevalence among this cohort. The threats to health system integrity and capacity during crises, such as the COVID-19 pandemic, also underscore the importance of ACP. For example, ACP may help to mitigate health care workers' ethical and triage decision making in instances where the health care system has insufficient resources to provide life-sustaining treatment to all persons nearing the end of life, and when it may be difficult or impossible to assess patients' preferences regarding treatment.

## 4.3. Practice implications

Our findings also provide important guideposts for family members and healthcare providers initiating informal care conversations to elicit wishes, as well as those developing methods to increase formal advance care planning. Future research and interventions should incorporate these individual-level and interpersonal factors, in addition to health services interventions to increase ACP.

A desire to mitigate proxies' decision-making burden was a significant motivator for ACP conversations, more prevalent and more salient than the desire for value concordant care at the end of life. Similarly, awareness of negative EOL experiences in their social networks may have motivated adults to have these conversations. These socially-based motivations and triggers are highly relevant to tools, including non-medical tools such as conversation-based games, that are designed to spur ACP-related conversations and behaviors [59–62]. Increasing the general public's awareness of these tools may increase uptake, and in turn these tools provide actionable steps toward ACP. These tools may also have utility for increasing confidence and self-efficacy, which we found was associated with both informal and formal ACP.

Finally, health care providers appear to have an especially salient role in ACP uptake. Reviews have found that more successful interventions in the health care setting address ACP over multiple visits, as opposed to "single dose" interventions or providing passive educational information [63]. The critical role of clinicians' authority in initiating these conversations suggests that expanded training of medical professionals about ACP could yield more advance care planning, supporting patient preferences, reducing ambiguity, and ultimately improving appropriateness of use of healthcare resources. Still, there are competing demands on clinicians' time and the health care system that can impede ACP efforts [64,65]. There remains a need for pragmatic ACP interventions that are sustainable in the real world of clinical practice, beyond experimental or evaluation programs [64].

## CRedit authorship contribution statement

**Daniel Siconolfi:** Conceptualization, Methodology, Investigation, Formal analysis, Writing - original draft, Writing - review & editing, Project administration. **Julia Bandini:** Conceptualization, Writing - original draft, Writing - review & editing. **Emily Chen:** Conceptualization, Methodology, Investigation, Writing - original draft, Writing - review & editing, Project administration, Funding acquisition.

## Declaration of Competing Interest

The authors have no conflicts of interest to declare.

## Acknowledgements

The authors thank Lori Frank for her contributions to the survey development and critical review of the early manuscript, and Elie Ohana for supporting early descriptive analysis. We also thank Ammarah Mahmud for her support developing the survey instrument. This research was funded by the National Institute on Aging at the National Institutes of Health (R21AG054803; PI: Chen). The content is solely the responsibility of the authors, and does not necessarily represent the official views of the National Institutes of Health.

## References

- [1] Institute of Medicine Committee on Approaching Death: Addressing Key End-of-Life Issues, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, National Academies Press, Washington, DC, 2015.
- [2] C.H.M. Houben, M.A. Spruit, M.T.J. Groenen, E.F.M. Wouters, D.J.A. Janssen, Efficacy of advance care planning: a systematic review and meta-analysis, *J. Am. Med. Dir. Assoc.* 15 (7) (2014) 477–489.
- [3] M.J. Silveira, S.Y. Kim, K.M. Langa, Advance directives and outcomes of surrogate decision making before death, *N. Engl. J. Med.* 362 (13) (2010) 1211–1218.
- [4] A.A. Wright, B. Zhang, A. Ray, J.W. Mack, E. Trice, T. Balboni, S.L. Mitchell, V.A. Jackson, S.D. Block, P.K. Maciejewski, Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment, *JAMA* 300 (14) (2008) 1665–1673.
- [5] A. Brinkman-Stoppelenburg, J.A. Rietjens, A. van der Heide, The effects of advance care planning on end-of-life care: a systematic review, *Palliat. Med.* 28 (8) (2014) 1000–1025.
- [6] K.E. Bischoff, R. Sudore, Y. Miao, W.J. Boscardin, A.K. Smith, Advance care planning and the quality of end-of-life care in older adults, *J. Am. Geriatr. Soc.* 61 (2) (2013) 209–214.
- [7] E.K. Vig, H. Starks, J.S. Taylor, E.K. Hopley, K. Fryer-Edwards, Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others, *J. Gen. Intern. Med.* 22 (9) (2007) 1274–1279.
- [8] D. Wendler, A. Rid, Systematic review: the effect on surrogates of making treatment decisions for others, *Ann. Intern. Med.* 154 (5) (2011) 336–346.
- [9] K.M. Detering, A.D. Hancock, M.C. Reade, W. Silvester, The impact of advance care planning on end of life care in elderly patients: randomised controlled trial, *BMJ* 340 (2010) c1345.
- [10] W.F. Bond, M. Kim, C.M. Franciskovich, J.E. Weinberg, J.D. Svendsen, L.S. Fehr, A. Funk, R. Sawicki, C.V. Asche, Advance care planning in an accountable care organization is associated with increased advanced directive documentation and decreased costs, *J. Palliat. Med.* 21 (4) (2018) 489–502.
- [11] N. Khandelwal, D.C. Benkeser, N.B. Coe, J.R. Curtis, Potential influence of advance care planning and palliative care consultation on ICU costs for patients with chronic and serious illness, *Crit. Care Med.* 44 (8) (2016) 1474–1481.
- [12] B. Zhang, A.A. Wright, H.A. Huskamp, M.E. Nilsson, M.L. Maciejewski, C.C. Earle, S.D. Block, P.K. Maciejewski, H.G. Prigerson, Health care costs in the last week of life: associations with end-of-life conversations, *Arch. Intern. Med.* 169 (5) (2009) 480–488.
- [13] C. Klingler, J. in der Schmitt, G. Marckmann, Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations, *Palliat. Med.* 30 (5) (2016) 423–433.
- [14] K.N. Yadav, N.B. Gabler, E. Cooney, S. Kent, J. Kim, N. Herbst, A. Mante, S.D. Halpern, K.R. Courtright, Approximately one in three US adults completes any type of advance directive for end-of-life care, *Health Aff.* 36 (7) (2017) 1244–1251.
- [15] S.M. Moorman, M. Inoue, Persistent problems in end-of-life planning among young- and middle-aged American couples, *J. Gerontol. B Psychol. Sci. Soc. Sci.* 68 (1) (2013) 97–106.
- [16] J.A.C. Rietjens, R.L. Sudore, M. Connolly, J.J. van Delden, M.A. Drickamer, M. Droger, A. van der Heide, D.K. Heyland, D. Houttekier, D.J.A. Janssen, L. Orsi, S. Payne, J. Seymour, R.J. Jox, I.J. Korfage, Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care, *Lancet Oncol.* 18 (9) (2017) e543–e551.
- [17] M. Inoue, E. Ihara, A. Terrillion, Making your wishes known: who completes an advance directive and shares it with their health care team or loved ones? *J. Appl. Gerontol.* 38 (12) (2019) 1746–1762.
- [18] H.D. Lum, R.L. Sudore, Advance care planning and goals of care communication in older adults with cardiovascular disease and multi-morbidity, *Clin. Geriatr. Med.* 32 (2) (2016) 247–260.
- [19] D. Carr, E.A. Luth, Advance care planning: contemporary issues and future directions, *Innov Aging* 1 (1) (2017) igx012.
- [20] J.A. Tulskey, Beyond advance directives: importance of communication skills at the end of life, *JAMA* 294 (3) (2005) 359–365.
- [21] Y. Su, M. Yuki, K. Hirayama, The experiences and perspectives of family surrogate decision-makers: a systematic review of qualitative studies, *Patient Educ. Couns.* 103 (6) (2020) 1070–1081.
- [22] Y. Schenker, M. Crowley-Matoka, D. Dohan, G.A. Tiver, R.M. Arnold, D.B. White, I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU, *J. Gen. Intern. Med.* 27 (12) (2012) 1657–1665.
- [23] J. Chiachiaro, P. Buddadhumaruk, R.M. Arnold, D.B. White, Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients, *Ann. Am. Thorac. Soc.* 12 (10) (2015) 1528–1533.
- [24] K.L. Harrison, E.R. Adron, C.S. Ritchie, R.L. Sudore, A.K. Smith, Low completion and disparities in advance care planning activities among older Medicare beneficiaries, *JAMA Intern. Med.* 176 (12) (2016) 1872–1875.
- [25] I.A. Huang, J.M. Neuhaus, W. Chiong, Racial and ethnic differences in advance directive possession: role of demographic factors, religious affiliation, and personal health values in a national survey of older adults, *J. Palliat. Med.* 19 (2) (2016) 149–156.
- [26] C.S. Koss, T.A. Baker, Race differences in advance directive completion, *J. Aging Health* 29 (2) (2017) 324–342.
- [27] J.K. Rao, L.A. Anderson, F.C. Lin, J.P. Laux, Completion of advance directives among U.S. consumers, *Am. J. Preventative Med.* 46 (1) (2016) 65–70.
- [28] M.A. Clark, S.D. Person, A. Gosline, A.A. Gawande, S.D. Block, Racial and ethnic differences in advance care planning: results of a statewide population-based survey, *J. Palliat. Med.* 21 (8) (2018) 1078–1085.
- [29] M. Hong, E.H. Yi, K.J. Johnson, M.E. Adamek, Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: a systematic review of the current literature, *J. Immigr. Minor. Health* 20 (5) (2018) 1277–1287.
- [30] M. Inoue, The influence of sociodemographic and psychosocial factors on advance care planning, *J. Gerontol. Soc. Work* 59 (5) (2016) 401–422.
- [31] M. Pollard, M.D. Baird, The RAND American Life Panel: Technical Description, RAND Corporation, Santa Monica, CA, 2017.
- [32] E. Chen, D. Siconolfi, L. Frank, A. Mahmud, American Life Panel – Well Being 531 – Advance Care Planning, RAND American Life Panel, 2019.
- [33] E.K. Chen, Family and Social Networks for Age-Related Planning Conversations: Characteristics and Variability, Gerontological Society of America, Gerontological Society of America, Phoenix, AZ, 2019 p. S668.
- [34] I. Pilowsky, Dimensions of hypochondriasis, *Br. J. Psychiatry* 113 (494) (1967) 89–93.
- [35] N.C. Pearce, R.A. Parks, WLS Staff, User's Guide, Wisconsin Longitudinal Study Instrumentation: 1957 to 2010, (2011) Madison, WI.
- [36] World Health Organization, The World Health Organization Quality of Life (WHOQOL)–BREF, World Health Organization, Geneva, Switzerland, 2004.
- [37] StataCorp, Stata Statistical Software: Release 16, StataCorp LP, College Station, TX, 2019.
- [38] J.S. Long, J. Freese, Regression Models for Categorical Dependent Variables Using Stata, 3rd edition, Stata Press, College Station, TX, 2014.
- [39] D. McFadden, Quantitative methods for analysing travel behavior of individuals: some recent developments, in: D.A. Hensher, P.R. Stopher (Eds.), Behavioral Travel Modeling, Croom Helm, London, 1979, pp. 279–318.
- [40] D. McFadden, Conditional logit analysis of qualitative choice behavior, in: P. Zarembka (Ed.), Frontiers in Econometrics, Academic Press, New York, NY, 1974, pp. 104–142.
- [41] T. Sinuff, P. Dodek, J.J. You, D. Barwich, C. Tayler, J. Downar, M. Hartwick, C. Frank, H.T. Stelfox, D.K. Heyland, Improving end-of-life communication and decision making: the development of a conceptual framework and quality indicators, *J. Pain Symptom Manage.* 49 (6) (2015) 1070–1080.
- [42] R.L. Sudore, D.K. Heyland, H.D. Lum, J.A.C. Rietjens, I.J. Korfage, C.S. Ritchie, L. C. Hanson, D.E. Meier, S.Z. Pantilat, K. Lorenz, M. Howard, M.J. Green, J.E. Simon, M.A. Feuz, J.J. You, Outcomes that define successful advance care planning: a Delphi panel consensus, *J. Pain Symptom Manage.* 55 (2) (2018) 245–255.e8.
- [43] O.P. Geerse, D.J. Lamas, R.E. Bernacki, J.J. Sanders, J. Paladino, A.J. Berendsen, T.J. N. Hiltermann, C. Lindvall, E.K. Fromme, S.D. Block, Adherence and concordance between serious illness care planning conversations and oncology clinician documentation among patients with advanced cancer, *J. Palliat. Med.* (2020) [in press].
- [44] J.A. Billings, R. Bernacki, Strategic targeting of advance care planning interventions: the Goldilocks phenomenon, *JAMA Intern. Med.* 174 (4) (2014) 620–624.
- [45] A.M. Scott, Communication about end-of-life health decisions, *Ann. Int. Commun. Assoc.* 38 (1) (2014) 243–277.
- [46] C.S. Koss, D. Jensen, Going it alone: advance directive discordance in older married couples, *J. Appl. Gerontol.* (2019) 733464819884439.
- [47] L. Sessanna, M.A. Jezewski, Advance directive decision making among independent community-dwelling older adults, *J. Appl. Gerontol.* 27 (4) (2008) 486–510.
- [48] D. Carr, D. Khodyakov, End-of-life health care planning among young-old adults: an assessment of psychosocial influences, *J. Gerontol. B Psychol. Sci. Soc. Sci.* 62 (2) (2007) S135–41.
- [49] J. Simon, P. Porterfield, S.R. Bouchal, D. Heyland, 'Not yet' and 'Just ask': barriers and facilitators to advance care planning—a qualitative descriptive study of the perspectives of seriously ill, older patients and their families, *BMJ Support. Palliat. Care* 5 (1) (2015) 54–62.
- [50] D. Carr, Racial and ethnic differences in advance care planning: identifying surrogate patterns and obstacles, *J. Aging Health* 24 (6) (2012) 923–947.
- [51] P.J. Cantwell, Panel conditioning, in: P.J. Lavrakas (Ed.), Encyclopedia of Survey Research Methods, Sage, Thousand Oaks, CA, 2011, pp. 567.

- [52] J. Clinton, Panel bias from attrition and conditioning: a case study of the Knowledge Networks Panel, American Association for Public Opinion Research, 55th, Montreal, Canada (2001).
- [53] L.J. Van Scoy, A.M. Scott, J.M. Reading, C.H. Chuang, V.M. Chinchilli, B.H. Levi, M. J. Green, From theory to practice: measuring end-of-life communication quality using Multiple Goals Theory, *Patient Educ. Couns.* 100 (5) (2017) 909–918.
- [54] J.P. Caughlin, Invited Review Article: a multiple goals theory of personal relationships: conceptual integration and program overview, *J. Soc. Pers. Relat.* 27 (6) (2010) 824–848.
- [55] C. Mithers, Baby boomers grew up fearing nuclear war. Now we fear something too small to see, 2020. <https://www.latimes.com/opinion/story/2020-03-25/how-coronavirus-has-changed-baby-boomers-perceptions-of-ourselves>. (Accessed March 31, 2020).
- [56] K. Hafner, 'A heart-wrenching thing': Hospital bans on visits devastate families, 2020. <https://www.nytimes.com/2020/03/29/health/coronavirus-hospital-visit-ban.html>. (Accessed March 31, 2020).
- [57] S.B. Garland, What to know about making a will in the age of coronavirus, 2020. <https://www.nytimes.com/article/what-is-a-will-and-how-to-make-one.html>. (Accessed March 31, 2020).
- [58] J. Aleccia, Talking to your family about death and medical directives, amid coronavirus, 2020. <https://www.cnn.com/2020/03/31/health/family-death-planning-coronavirus-khn-wellness/index.html>. (Accessed March 31, 2020).
- [59] C.P. Sabatino, Advance care planning tools that educate, engage, and empower, *Public Policy Aging Rep.* 24 (3) (2014) 107–111.
- [60] L.J. Van Scoy, B.H. Levi, P. Witt, C. Bramble, C. Richardson, I. Putzig, A.R. Levi, E. Wasserman, V. Chinchilli, A. Tucci, M.J. Green, Association of participation in an end-of-life conversation game with advance care planning behavior and perspectives among African American individuals, *JAMA Netw Open* 3 (5) (2020)e204315.
- [61] L.J. Van Scoy, M.J. Green, J.M. Reading, A.M. Scott, C.H. Chuang, B.H. Levi, Can playing an end-of-life conversation game motivate people to engage in advance care planning? *Am. J. Hosp. Palliat. Care* 34 (8) (2017) 754–761.
- [62] L.J. Van Scoy, J.M. Reading, A.M. Scott, C. Chuang, B.H. Levi, M.J. Green, Exploring the topics discussed during a conversation card game about death and dying: a content analysis, *J. Pain Symptom Manage.* 52 (5) (2016) 655–662.
- [63] M.I. Tamayo-Velazquez, P. Simon-Lorda, R. Villegas-Portero, C. Higuera-Callejon, J.F. Garcia-Gutierrez, F. Martinez-Pecino, I.M. Barrio-Cantalejo, Interventions to promote the use of advance directives: an overview of systematic reviews, *Patient Educ. Couns.* 80 (1) (2010) 10–20.
- [64] S. Lund, A. Richardson, C. May, Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies, *PLoS One* 10 (2) (2015)e0116629.
- [65] E. Weathers, R. O'Caomh, N. Cornally, C. Fitzgerald, T. Kearns, A. Coffey, E. Daly, R. O'Sullivan, C. McGlade, D.W. Molloy, Advance care planning: a systematic review of randomised controlled trials conducted with older adults, *Maturitas* 91 (2016) 101–109.