

## Research Report

# Insufficient Advance Care Planning? Correlates of Planning Without Personal Conversations

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Received: February 19, 2020; Editorial Decision Date: June 1, 2020

**Decision Editor:** J. Jill Suitor, PhD, FGSA

## Abstract

**Objectives:** Advance care planning (ACP) typically comprises formal preparations (i.e., living will and/or durable power of attorney for health care) and informal discussions with family members and health care providers. However, some people complete formal documents without discussing them with others. If they become incapacitated, their appointed decision makers may lack guidance on how to interpret or enact their formal wishes. We document the prevalence and correlates of this partial approach to ACP.

**Method:** Using multinomial logistic regression models and data from a U.S. sample of 4,836 older adults in the 2018 wave of the National Health and Aging Trends Study (NHATS), this brief report evaluated associations between social integration indicators and the odds of completing (a) both discussions and formal plans (two-pronged ACP), (b) discussions only, (c) no ACP, and (d) formal ACP only (reference category). We adjust for demographic and health characteristics established as correlates of ACP.

**Results:** A minority (15%) of NHATS participants reported formal plans without having discussed them. Indicators of social isolation (e.g., smaller social networks and fewer social activities) increased the odds of engaging in formal planning only compared to two-pronged ACP. Socioeconomic disadvantage and probable dementia reduced the odds of having end-of-life conversations, whether as one's only preparation or in tandem with formal preparations.

**Discussion:** Socially isolated persons are especially likely to do formal planning only, which is considered less effective than two-pronged ACP. Health care professionals should recognize that older adults with few kin may require additional support and guidance when doing ACP.

**Keywords:** End of life, Formal planning, Social isolation

Most deaths of older adults in the United States are attributable to chronic diseases such as heart disease, cancer, stroke, and dementia (Kochanek, Murphy, Xu, & Arias, 2019). Dying patients and their families face difficult decisions regarding medical treatments they desire (or reject) at the end of life (EOL) (Carr & Luth, 2017). To help ensure that these treatment preferences are documented and

respected by care providers, individuals can engage in advance care planning (ACP) when they are still cognitively intact. ACP comprises formal and informal components: Formal ACP includes a living will, a legal document specifying the medical treatments one would like to receive, and a durable power of attorney for health care (DPAHC), which designates an individual to make decisions on be-

half of a patient who is unable to make those decisions. Informal planning refers to discussions with practitioners and others regarding one's preferences, values, and general orientation toward curative versus palliative measures (Sudore & Fried, 2010).

ACP is most effective when formal documents are executed following conversations with those persons who may represent the patient in the decision-making process (Bomba, 2017). Although families are integral to EOL decision-making, with spouses and adult children most frequently serving as DPAHC (Carr & Khodyakov, 2007), their accuracy in reporting the patient's preferences is no higher than chance, in part because they might not have discussed such matters (Moorman & Carr, 2008). Consequently, meaningful discussions among patients, family, and care providers, including physicians, are critical to ensuring that the designated proxy and other kin understand and are comfortable representing the patient's choices and that formal ACP documents accurately reflect the preferences and values conveyed during the discussion.

The recommended two-pronged approach (formal planning with discussions) is the most common strategy adopted by older U.S. adults. Among white high school graduates born in the late 1930s, half reported two-pronged ACP, yet only 5% engaged in formal planning without having discussed these plans (Carr, Moorman, & Boerner, 2013). We know little about this small subpopulation because researchers have excluded it from analyses due to sample size, or combined it with those who have done two-pronged planning, potentially concealing the correlates and consequences of this (presumably) inferior approach to ACP.

Understanding who engages in formal planning only is an important goal, with implications for practice and policy. First, without conversations, patients and their care providers cannot gauge whether the designated DPAHC is indeed "the right health care agent" (Bomba, 2017, p. 2) who is willing, able, and available to execute the patient's requests. Second, health care proxies may feel unprepared for and overwhelmed by the responsibility of making medical decisions on behalf of a patient without knowing their preferences. This lack of preparation may be particularly acute when the active stage of dying starts shortly after the onset of illness, as is the case with COVID-19 and other infectious diseases (Moorman, Boerner, & Carr, *in press*). Third, conflict may arise within the patient's social network if family members and care providers did not hear, understand, and discuss the patient's preferences. Therefore, documenting the characteristics of this subgroup is critical, to identify who is at risk of engaging in a practice that may reduce quality of care at the EOL.

## Current Study

In this brief report, we use National Health and Aging Trends Study (NHATS) data to examine correlates of

engaging in formal planning only (relative to informal only, two-pronged, or no planning). We explore whether persons with poorer social integration are more likely to engage in formal planning only and evaluate the extent to which such patterns persist net of demographic and health characteristics that are established correlates of ACP (Carr & Luth, 2017).

We conceptualize ACP as a pro-active health behavior, intended to convey one's EOL treatment preferences and ultimately enhance the quality of care and EOL well-being (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Theoretical and empirical work underscores the importance of social integration for facilitating behaviors that enhance well-being; married persons (Umberson, 1992), parents (Carr & Khodyakov, 2007), persons with a confidante, and those with ample and supportive social networks (Martire & Franks, 2014) are especially likely to engage in health-enhancing behaviors, due in part to receipt of psychological and instrumental support. Significant others also serve a social control function, encouraging healthy and discouraging unhealthy behaviors (Umberson, 1992) or serving as a role model for such practices (Carr, 2012).

We hypothesize that persons who are less socially integrated, operationalized as those without children, unmarried persons, and those with fewer social network members and social activities are particularly likely to engage in formal planning only. This may partly reflect the importance of social support for health-enhancing practices, as well as the fact that socially isolated persons have access to fewer (or no) discussion partners. We further examine the extent to which linkages between social isolation and formal planning reflect potential confounds like socioeconomic status (SES) and poor health, which may render one vulnerable to both social isolation and formal planning only.

## Method

### Data

Data are from the 2018 wave of the NHATS, an annual longitudinal survey of Medicare beneficiaries aged 65 and older residing in the contiguous United States, with oversampling of those aged 90 and older and non-Hispanic blacks (Montaquila, Spillman, & Kasper, 2012). In-person interviews were conducted in English or Spanish. The 2018 (Wave 8) sample included 5,547 persons (response rate of 94%), where all community-dwelling participants ( $n = 4,946$ ) were asked to complete questions regarding EOL care planning. (Nursing home residents did not receive the ACP module.) Participants who had a missing response or responded "do not know" to the primary outcome measure ( $n = 95$ ) were excluded from the analytic sample. Right, we talked about this. Nursing home residents received an abbreviated survey that did not contain

ACP questions—most of the information for them is from a proxy and is about the facility they live in.

## Measures

Our focal outcome is ACP comprising the categories of formal planning only (reference group), EOL discussions only, two-pronged (both formal planning and discussions), or no ACP. Respondents were asked whether they have “talked to anyone about the types of medical treatment you would want or not want if you became seriously ill in the future”; “made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself”; and “a living will or advance directive?” Half of the participants reported two-pronged ACP; one quarter did no ACP. Formal planning only (15%) and discussions only (11%) were less common.

Social integration measures include parental status (1 = has children); marital status (divorced/separated, widowed, never married, and married); total number of social network members; and total number of social activities. Social network was assessed with the question: “Looking back over the last year, who are the people you talked with most often about important things,” including “good or bad things that happen to you, problems you are having, or important concerns you may have.” Participants could list up to five persons. For social activities, participants indicate which of the following they have done in the past month: visited in person with friends or family not living with you, attended religious services, participated in other organized activities (besides religious services), and gone out for enjoyment. This measure ranged from 0 to 4.

We adjusted for potential confounds, including demographic characteristics (age, gender, education, household income, racial/ethnic minority, and home ownership), and health. Health measures included self-rated health, number of comorbid chronic conditions, number of functional impairments, self-reported hospitalizations (past year), depressive symptoms based on a Patient Health Questionnaire score greater than 3 (Kroenke, Spitzer, Williams, & Löwe, 2009), and probable dementia based on criteria established by NHATS (Kasper, Freedman, & Spillman, 2013). Descriptive statistics for all measures are presented in [Supplementary Table 1](#).

## Analytic Strategy

We used multinomial logistic regression models to evaluate the association between social integration indicators and the outcome categories of (a) both discussions and formal plans (two-pronged), (b) discussions only, or (c) no ACP, compared to formal plans only (reference category). We present results for an unadjusted model (social integration measures only) and an adjusted model, accounting

for demographic and health characteristics. To address the concern that persons with probable dementia (14% of the sample) might provide inaccurate reports of their ACP, we carried out sensitivity analyses excluding these cases. The results for all multivariate analyses were identical for those obtained in the full sample, thus we retain the full sample in this analysis.

## Results

The multivariate results given in [Supplementary Table 2](#) reveal that whites and persons with more social activities, older age, higher income, homeownership, and recent hospitalizations are less likely to be non-planners relative to formal planners only. None of the social integration variables distinguished between persons doing either type of one-pronged planning (formal only vs discussions only). However, health and demographic factors including older age, higher income, and probable dementia reduced the odds of having discussions only compared to formal planning only. Conversely, women and more highly educated persons were more likely to have discussions only, compared to formal plans only. Finally, never married persons, racial/ethnic minorities, and those with probable dementia were less likely to do two-pronged ACP relative to formal planning only, whereas women, more highly educated persons, and those with a larger social network and more social activities had higher odds of two-pronged ACP compared to formal planning only.

## Discussion

This is the first study we know of to document the characteristics of persons who make formal EOL plans without having had discussions about those plans. The NHATS' large sample size enables adequately powered analyses of this small yet significant subgroup. Results support our hypothesis that social isolation partially explains why some older adults do formal planning only. Relative to those who did two-pronged ACP, widely considered the most effective approach, persons in the formal planning group had significantly smaller social networks and engaged in fewer social activities. Formal planning may be a default option for those who lack confidantes or have limited social contacts who may encourage or facilitate pro-active health behaviors like ACP. Such barriers to EOL conversations may seem even more insurmountable under current conditions of social distancing to protect older adults from COVID-19 infection risk.

Persons doing formal planning only had other characteristics linked with social isolation, most notably advanced age, low SES, and probable dementia. For instance, college graduates are more likely to do two-pronged ACP or have discussions only whereas persons with probable dementia are less likely to do so, relative to those doing

formal planning only. We also confirm prior research showing that lower SES, ethnic minority status, and not owning a home are significant correlates of not engaging in ACP (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Teno et al., 2007). It is important to keep in mind that a lack of ACP is associated with a greater risk of poor quality EOL care and care that is discordant with one's treatment preferences (Bischoff et al., 2013).

Although public policies like the Patient Self-Determination Act and programs like the Respecting Choices initiative (Briggs, 2013) focused on increasing advance directive completion rates, our results suggest that other initiatives are required to encourage and facilitate conversations alongside formal planning, such as The Conversation Project (Sokol-Hessner et al., 2019). Socially isolated persons, including oldest-old persons and those with sparse economic resources, may not have access to family or friends to foster such discussions, so health care providers should be mindful of raising such conversations. The current pandemic has forced reduced social contact, especially among those with elevated infection risk, underscoring the vital role of health care providers in encouraging EOL planning conversations, as social network access may be severely limited for many. The ACA provision of reimbursing health care providers for their EOL conversations with Medicare beneficiaries, implemented in 2016, was an essential first step (van Zyl & Gross, 2018)—allowing care providers to become more actively involved in supporting their patients' EOL care planning. This will be particularly important for isolated older adults who are disproportionately completing formal documents without discussion and consequently may find their preferences unknown, misunderstood, or neglected at the EOL.

## Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

## Funding

None reported.

## Author Contributions

K. Boerner, D. Carr, S. M. Moorman, and K. Ornstein planned the study together. S. M. Moorman and K. Ornstein performed statistical analyses. K. Boerner drafted the manuscript. All authors revised the manuscript.

## Conflict of Interest

None reported.

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