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By Kuldeep N. Yadav, Nicole B. Gabler, Elizabeth Cooney, Saida Kent, Jennifer Kim, Nicole Herbst, Adjoa Mante, Scott D. Halpern, and Katherine R. Courtright

Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care

Kuldeep N. Yadav is a research coordinator in the Palliative and Advanced Illness Research Center, Perelman School of Medicine, University of Pennsylvania, in Philadelphia.

Nicole B. Gabler is a senior research investigator in the Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania.

Elizabeth Cooney is director of research operations of the Palliative and Advanced Illness Research Center and assistant director of the Fostering Improvement in End-of-Life Decision Science Program, Perelman School of Medicine, University of Pennsylvania.

Saida Kent is a medical student at the University of Kentucky College of Medicine, in Lexington, and a research assistant in the Palliative and Advanced Illness Research Center, University of Pennsylvania.

Jennifer Kim is a medical student at Thomas Jefferson University, in Philadelphia.

Nicole Herbst is a medical resident at Boston Medical Center, in Massachusetts.

Adjoa Mante is an undergraduate student at Princeton University, in New Jersey.

ABSTRACT Efforts to promote the completion of advance directives implicitly assume that completion rates of these documents, which help ensure care consistent with people's preferences in the event of incapacity, are undesirably low. However, data regarding completion of advance directives in the United States are inconsistent and of variable quality. We systematically reviewed studies published in the period 2011–16 to determine the proportion of US adults with a completed living will, health care power of attorney, or both. Among the 795,909 people in the 150 studies we analyzed, 36.7 percent had completed an advance directive, including 29.3 percent with living wills. These proportions were similar across the years reviewed. Similar proportions of patients with chronic illnesses (38.2 percent) and healthy adults (32.7 percent) had completed advance directives. The findings provide benchmarks for gauging future policies and practices designed to motivate completion of advance directives, particularly among those people most likely to benefit from having these documents on record.

The treatments Americans would choose near the end of life are often different from the treatments they receive.^{1–4} This disconnect between care desired and care received may lead to burdensome and potentially nonbeneficial therapies that can increase suffering for patients and caregivers⁵ and contribute significantly to health care costs.⁶ Advance directives, typically in the form of living wills and health care powers of attorney, are documents that offer patients a way to avoid unwanted care in the event of serious illness or incapacity. An advance directive is a formal legal document specifically authorized by state laws that individuals complete to be invoked if they become seriously ill and unable to make decisions. People can revoke or change the documents at any time. A durable health care power of attorney designates a surrogate or proxy—a person who will make treat-

ment decisions for the patient if the patient becomes too incapacitated to make such decisions. A living will is a written statement specifying preferences regarding the use of life-sustaining therapies and other medical treatments in the event of incapacity or terminal illness. Observational studies suggest that there are benefits to completing advance directives, with patients in the United States who complete such a directive being less likely to die in the hospital^{7–10} and more likely to receive care that is consistent with their preferences,^{9,11} to have surrogates who report better communication with physicians near the end of life,¹⁰ and to receive less costly care in certain regions.⁸

There have been multiple large-scale educational^{12,13} and legal¹⁴ efforts to promote the completion of advance directives over the past few decades. However, several questions remain unanswered regarding the impact of these

initiatives—questions that are particularly relevant given Medicare’s decision to reimburse physicians for advance care planning counseling, effective January 1, 2016. We conducted a systematic review of the data on the prevalence of advance directives among US adults collected before this policy change, to determine how many Americans had an advance directive, both overall and specifically among people most likely to benefit from them, and how advance directive completion rates have changed over time. Answering these questions may help identify opportunities for improvement and establish benchmarks against which to gauge the success of ongoing and future efforts to motivate people to complete advance directives.

Study Data And Methods

OVERVIEW We performed a systematic review and meta-analysis of studies published in the period 2011–16 that reported a completion proportion of advance directives among US adults. The Institutional Review Board of the University of Pennsylvania deemed this research exempt from review. We registered this study prospectively with PROSPERO, the international register of systematic reviews,¹⁵ on April 27, 2015 (Registration No. CRD42015019661). Our methods followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for article review and data extraction (see online Appendix Exhibit A).¹⁶

All statistical analyses were performed in RStudio (version 1.0.136), using the R language (version 3.3.3) and R packages meta (version 4.8-1), metaphor (version 1.9-9), and ggplot2 (version 2.2.1).

SELECTION CRITERIA To be included in our study, articles had to be written in English, have been published in a peer-reviewed journal, be about a population that included US adults (ages eighteen and older), and report original data on advance directive completion at the patient level. Only the baseline or control-group prevalence was included for articles that reported on an advance care planning intervention. Among articles that reported on duplicate cohorts, we retained the one that described the most recently collected data, or the larger sample size if the data collection period was the same. Finally, we excluded studies that included Physician Orders for Life-Sustaining Treatment (POLST) forms or do-not-resuscitate, do-not-intubate, or do-not-hospitalize orders as advance directives.

DATA SOURCES AND SEARCH We used a systematic three-part search strategy. First, we searched for articles published between January 1, 2011, and December 31, 2016, in the following six bio-

medical databases: PubMed, Embase, CINAHL, Scopus, Web of Science, and ProQuest. We used a standardized list of search terms that we chose in consultation with biomedical research librarians (for a more complete description of our research strategy, see Appendix Exhibit B).¹⁶ Second, using Web of Science, we conducted a cited reference search for all articles published during the review time frame that cited one of three high-impact articles regarding advance directive completion that were published before 2011.^{11,17,18} Finally, we hand-searched the citations in all of the articles that satisfied our inclusion criteria to capture any additional articles eligible for inclusion.

DATA EXTRACTION All data were extracted independently and in duplicate by trained abstractors (Kuldeep Yadav, Nicole Gabler, Saida Kent, Jennifer Kim, Nicole Herbst, and Adjoa Mante) using a standardized protocol. The abstracts of all articles identified in the data search were screened to determine if they met our inclusion criteria. Articles that did meet the criteria were fully abstracted using the Research Electronic Data Capture (REDCap) platform¹⁹ in the period March–August 2016 and in April 2017. Any disagreements among abstractors were resolved by Katherine Courtright’s arbitration.

The information collected included article characteristics, population characteristics, and the primary outcome. Article characteristics were publication year (2011–16), funding source (industry, nonindustry, or not specified), primary disease, population type (patient or healthy adult), type of advance directive (living will or health care power of attorney), and method of advance directive assessment (medical chart review or report by patient or surrogate). Population characteristics were age, sex, race, ethnicity, patient type (nursing home, hospice or palliative care, inpatient, or outpatient), and healthy adult type (community dweller or medical personnel).

For purposes of this review, the primary outcome of “any type of advance directive” was categorized into “living will,” “health care power of attorney,” and “advance directive—undefined.” The latter category consisted of studies that reported a combined rate of completion for living wills and health care powers of attorney or did not specify the type of advance directive. For each category, the completion proportion was defined as the number of completed documents out of the total denominator for that category. For articles that reported proportions for more than one type of advance directive without mutual exclusivity, we included the largest proportion in our analysis of the primary outcome of any advance directive. Thus, we acknowledged that either a living will or a health care power of

Scott D. Halpern is director of the Palliative and Advanced Illness Research Center, director of the Fostering Improvement in End-of-Life Decision Science Program, and an associate professor of medicine, epidemiology, and medical ethics and health policy, all at the Perelman School of Medicine, University of Pennsylvania.

Katherine R. Courtright (katherine.courtright@uphs.upenn.edu) is an instructor of medicine in the Division of Pulmonary, Allergy, and Critical Care, the Palliative and Advanced Illness Research Center, and the Fostering Improvement in End-of-Life Decision Science Program, all at the Perelman School of Medicine, University of Pennsylvania.

attorney was considered an advance directive, but we did not count the outcome twice.

DATA SYNTHESIS Descriptive statistics were used to summarize article and population characteristics. Discrete variables were described as percentages using fixed-effects meta-analytic techniques. Study heterogeneity was assessed using Cochran's Q and the I^2 statistic.²⁰ Because of significant heterogeneity across studies for all outcomes, we performed a random-effects meta-analysis using the method of Rebecca DerSimonian and Nan Laird²¹—which adjusts the standard errors of the study estimates to account for study-specific heterogeneity, such as sample size—to determine overall completion proportions for any advance directive and each category (living will, health care power of attorney, and advance directive—undefined).

We performed several subgroup analyses for the primary outcome of any advance directive. We first examined differences in advance directive completion over time. Because most studies reported a single proportion spanning multiple years of data collection, we considered whether publication year could serve as a proxy for the period of data collection. To assess for correlation between publication year and data collection period, we used a Spearman's rank coefficient for the sixty studies that collected data over a one-year period ($r_s = 0.70$; $p < 0.001$), and we used the median year of data collection for the forty-six studies that collected data over multiple years ($r_s = 0.71$; $p < 0.001$). We excluded the forty-four studies that did not report the data collection period. Because studies with later publication dates generally reported on later data collection periods, we report advance directive completion proportions by publication year. However, in a restricted analysis, we used a chi-square test to compare the completion proportion in studies that reported on data collected in 2010 or later and the proportion in studies that reported on data collected before 2010.

We also used chi-square tests to compare advance directive completion rates in different subgroups of studies. The subgroups were those that used: chart review and reports by patients or surrogates (the two methods of advance directive assessment); patients and healthy adult populations; various types of patients (such as nursing home patients); older adults eligible for Medicare and younger adults; and patients with various specific diseases.

Finally, to further explore significant sources of study-level heterogeneity, we performed a series of meta-regressions examining participant age (those ages sixty-five and older versus younger people), sample size (quartiles of the overall distribution), and method of advance directive

assessment.²⁰ For all analyses, differences were considered significant at $p < 0.05$.

RISK-OF-BIAS ASSESSMENT Risk of bias in reported advance directive completion was determined by the method of advance directive assessment, with the assumption that prevalence determined by objective methods had less risk of bias than self-report methods, which could be subject to recall bias. Therefore, articles that used medical chart review were considered low risk, while those that relied on patient or surrogate reports were considered high risk.

LIMITATIONS Our systematic review had several limitations. First, it was designed to assess the recent prevalence of advance directives among US adults. Despite the use of an expert-informed systematic search strategy, we may have missed studies reporting relevant data. Indeed, we found a few additional studies during our review of citations in eligible articles, which indicated that our electronic search strategy was not fully sensitive.

Second, the quality and manner of data reporting for participants' characteristics across the studies limited our ability to assess advance directive prevalence among populations with various demographic characteristics. Instead, we summarize the data where possible to provide some insight into current gaps in the advance directive literature.

Third, all data regarding the presence of an advance directive in the studies we analyzed were collected in a retrospective manner—that is, by patient or surrogate recall or medical chart review. To the extent that ensuing recall and misclassification biases limited the original studies, they would in turn limit our systematic review.

Study Results

Our initial searches of the biomedical databases yielded 1,119 unique articles. Abstract screening resulted in 563 articles, which we reviewed in full. After applying exclusion criteria and adding articles identified in our review of citations, we had 150 articles for our analysis (for a graphical depiction of our inclusion process, see Appendix Exhibit C).¹⁶

DESCRIPTION OF STUDIES The 150 articles describe data that were collected in the period 2000–15. The articles had a median sample size of 201.5 (interquartile range: 77.2, 594.8). Forty-eight articles identified completion proportions for a living will, and 63 a health care power of attorney. Ninety-nine articles reported proportions for undefined advance directives (for more detailed descriptions of all 150 articles, see Appendix Exhibit D).¹⁶ Most of the studies (104) focused on patient populations, and the others

assessed healthy adults (46). Of the studies that reported on patients, 41 specified any advance directive completion by disease type—cancer in 19 studies, cardiovascular disease in 8, neurologic disease in 7, HIV/AIDS in 4, and renal disease in 3. The most common method of assessing for the presence of an advance directive was by patient or surrogate report (94), while the remaining 56 studies used medical chart review.

POPULATION CHARACTERISTICS Collectively, the 150 articles reported on 795,909 US adults (for more detailed population characteristics, see Appendix Exhibit E).¹⁶ Of the adults, 63.6 percent were female, 65.1 percent were white, 80.6 percent were ages sixty-five and older, and 62.7 percent were in a nursing home.

PREVALENCE OF ADVANCE DIRECTIVES The reported prevalence among all advance directive types ranged from 0.0 percent to 93.8 percent across all studies (Exhibit 1). The unadjusted proportion of any advance directive completion was 39.1 percent. Using random effect meta-analysis, we found an overall completion proportion for any advance directive of 36.7 percent (95% confidence interval: 33.3, 40.2). The unadjusted proportions of completion were 20.5 percent for living wills, 35.3 percent for health care powers of attorney, and 50.6 percent for undefined advance directives. Meta-analyses resulted in a completion proportions of 29.3 percent (95% CI: 25.0, 34.0) for living wills, 33.4 percent (95% CI: 29.5, 37.6) for health care powers of attorney, and 32.2 percent (95% CI: 27.2, 37.7) for undefined advance directives (see Appendix Exhibit F for more detailed results).¹⁶

Completion rates of any advance directive did

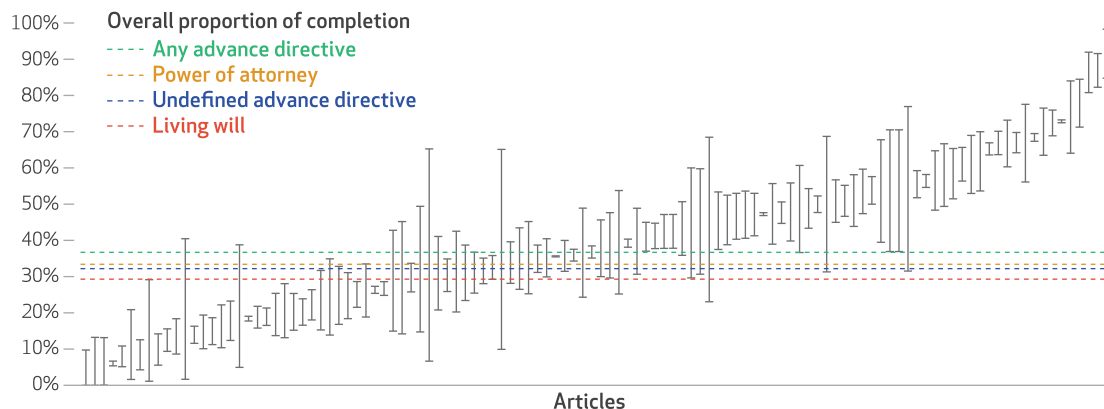
not differ significantly across study publication years ($p = 0.50$) (Exhibit 2). The results also did not differ between studies that collected data in the period 2010–15 and those that collected data before 2010 ($p = 0.96$) (see Appendix Exhibit G for more detailed results by year of data collection).¹⁶

Advance directive completion was nominally higher among patients (38.2 percent; 95% CI: 34.2, 42.3) than among healthy adults (32.7 percent; 95% CI: 24.7, 41.8), but this difference was not significant ($p = 0.26$) (data not shown). We found that completion was highest among those with neurologic disease and lowest among those with HIV/AIDS (Exhibit 3) (for more detailed results by primary disease, see Appendix Exhibit H).¹⁶

Among studies that assessed advance directive completion by chart review (studies that had a low risk of bias), the rate of completion of any advance directive was 32.0 percent (95% CI: 27.1, 37.4). The rate among studies using self-report (those with a high risk of bias) was 39.5 percent (95% CI: 34.4, 44.9). This contrast neared but did not achieve significance ($p = 0.05$) (for more detailed results by risk of bias, see Appendix Exhibit I).¹⁶ Patients ages sixty-five and older had a significantly greater completion proportion of any advance directive (45.6 percent; 95% CI: 40.6, 50.8), compared to younger adults (31.6 percent; 95% CI: 28.4, 35.0) ($p < 0.001$) (data not shown). There was a significant difference in any advance directive completion by patient type ($p < 0.001$), with the highest rates being among patients in hospice or palliative care (59.6 percent; 95% CI: 41.8, 75.1)

EXHIBIT 1

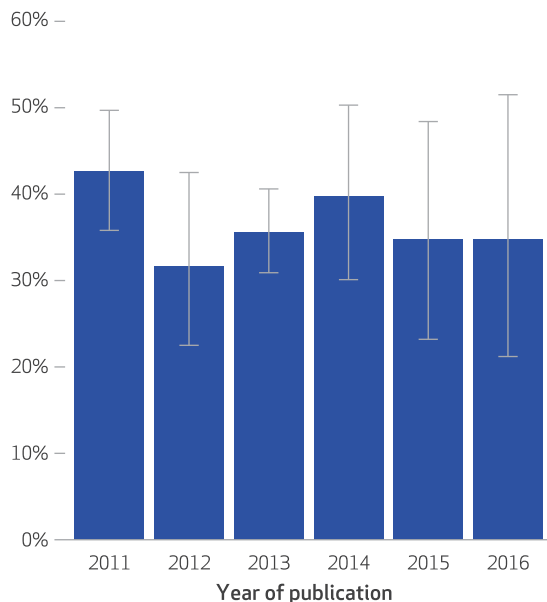
Percentages of people in the United States who had completed advance directives, as reported in 150 articles



SOURCE Authors' analysis. **NOTES** The error bars represent 95% confidence intervals. The articles are arranged by percentage of any advance directives completed (reported in all 150 articles). Of the articles, 99 reported percentages of undefined advance directives completed, 63 reported percentages of health care powers of attorney ("power of attorney") completed, and 48 reported percentages of living wills completed. The category of undefined advance directives is explained in the text.

EXHIBIT 2

Percentages of people in the United States who had completed advance directives as reported in 150 articles, by year of publication



SOURCE Authors' analysis. **NOTE** The error bars represent 95% confidence intervals.

and nursing home patients (50.1 percent; 95% CI: 42.1, 58.2).

Finally, in a series of meta-regressions examining age, risk of bias, and sample size as sources of heterogeneity, we found that only age was significant ($p = 0.01$). Despite this significance, the proportion of heterogeneity explained by the inclusion of age in the model was only 2.96 percent. Neither risk of bias nor sample size was a significant source of heterogeneity ($p < 0.05$), and the proportion of heterogeneity they explained was less than 1.00 percent for both.

Discussion

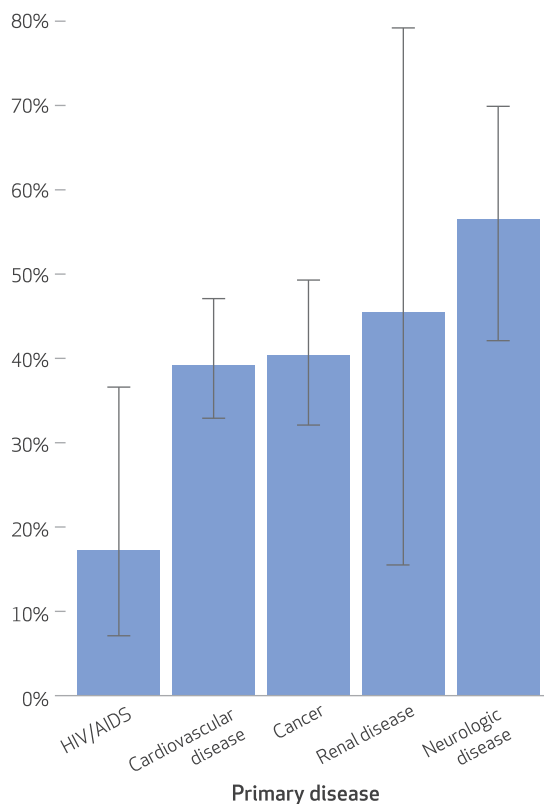
For nearly five decades, advance directives have been promoted as the primary tool for people to use in communicating their wishes regarding end-of-life care. This systematic review suggests that approximately one in three US adults has completed any type of advance directive. Although these estimates relied on multiple methods to assess advance directive completion, confidence in their accuracy is bolstered by our finding that this potential risk of bias did not influence our prevalence estimates. Other notable findings of this review are that the proportion of Americans with an advance directive does not seem to have changed, according to studies published in the past six years, and that similar

proportions of patients with chronic diseases and presumably healthy adults have completed advance directives.

There are several potential reasons for these findings. First, there is a common sentiment among health care providers that advance directives, and living wills in particular, have failed to live up to their promise,^{18,22–25} which may have led many providers not to promote their use. While a single document is unlikely to capture all of the possible situations one might face near the end of life, proponents of living wills cite evidence that most patients wish to protect their loved ones from the burdens of decision making^{26–30} and associated complications after the patient's death,^{28,31–34} and that even predictions by long-term partners of patients' desired end-of-life care are often inaccurate.^{35,36} Future efforts are needed to improve the content and format of advance

EXHIBIT 3

Percentages of people in the United States who had completed advance directives as reported in 150 articles, by primary disease



SOURCE Authors' analysis. **NOTES** The error bars represent 95% confidence intervals ($p < 0.001$ for the five-way comparison). Cardiovascular disease includes coronary artery disease, heart failure, and hypertension. Cancer includes solid and hematologic malignancies. Neurologic disease includes dementia and other neurodegenerative diseases, neuromuscular diseases, and cerebrovascular disease.

directives to better represent the substantive issues discussed in advance care planning conversations, such as patients' values and goals, in addition to specific care preferences.

Second, several legal formalities are required for executing an advance directive. For example, most states require that a directive be signed by two witnesses while also disqualifying many potential witnesses (for example, the patient's spouse and relatives, the person holding the patient's health care power of attorney, and the patient's health care provider or his or her staff members). Some states also require that an advance directive be notarized. Although these legal restrictions were put in place to protect patients, in fact they act as a barrier, particularly for vulnerable patients, and render advance directives less clinically useful.^{37–39} While there is a trend toward simplification of these statutory regulations, most of the few states that recognize oral instructional directives still require witnesses to validate the directives and do not permit someone to orally give another person health care power of attorney.⁴⁰

Third, misperceptions regarding POLST forms may have reduced efforts to increase completion rates for advance directives. This would be an unintended consequence of the uptake of the forms, because they differ from advance directives. The forms are intended to be portable physicians' orders providing out-of-hospital medical personnel with legal authority not to provide unwanted life-saving therapies.^{41,42} A living will also documents care preferences, but in addition, it enables broader and more nuanced goals to be documented for guiding health care providers and surrogate decision makers. Furthermore, it remains unclear whether the use of POLST forms improves the likelihood that the delivery of care matches what patients desire.⁴³

Fourth, it is possible that six years is not long enough to detect a significant change in advance directive completion rates. However, overall completion rates were similar between the studies that reported on data collected from earlier or later time periods. Finally, the considerable heterogeneity among reported prevalence across studies for any type of advance directive suggests that the pooled values presented in this systematic review should be interpreted and applied with some caution. Although age accounted for a small portion of the heterogeneity, advance directive reporting may vary across other patient-, surrogate-, physician-, or system-level factors not measured in the original studies, and thus not accounted for in our review.

This review's findings and implications should be considered in the larger context of evolving

advance care planning policy and practice. Two decades after the publication of *Approaching Death*,¹ the Institute of Medicine's landmark report calling for improvements in advance care planning and end-of-life care, Medicare instituted physician reimbursement for advance care planning conversations, including discussions of advance directives. However, translating such conversations into written goals and preferences that are accessible to health care providers caring for a patient near the end of his or her life remains an essential step. Indeed, in a recent consensus definition of *advance care planning*, an expert panel concluded that "documentation of [advance care planning] conversations and/or completion of legal documents is needed to ensure that the medical care provided aligns with a patient's preferences."⁴⁴ This approach is consistent with recommendations from the Institute of Medicine's more recent report, *Dying in America*,⁴⁵ which also highlights the need to incorporate such documentation reliably into electronic health records.

Efforts to increase completion rates of advance directives should be targeted to those most likely to benefit from the directives, to maximize their value and efficacy. Compared to an estimate of the prevalence of advance directive completion among patients with serious diseases before the first legislation advocating their broad use,^{14,46} our findings suggest that the prevalence of advance directives among patients has almost doubled (from 21 percent to 38 percent). While this increase is significant, the results of our review suggest that the majority of Americans remain without a completed advance directive even after thirty years of legislative and research initiatives. Thus, this review provides a current benchmark and comparisons of advance directive completion rates among different populations against which to measure the impact of Medicare reimbursement for advance care planning and future efforts to increase advance directive completion rates. To facilitate more precise assessments of the prevalence and efficacy of advance directives, future studies should take care to specify whether they assess a living will, a health care power of attorney, or both.

Moreover, there are problems associated with targeting initiatives to increase the use of advance directives too broadly.⁴⁷ Healthy people often cannot accurately predict their preferences in the event of future illness, a problem known as affective forecasting errors.^{48,49} By contrast, targeting patients with serious illnesses who are at risk for critical illness or death may increase the likelihood that the preferences they state in advance directives accurately and stably predict what they want in the event of their incapacity.⁵⁰

Thus, the observation in our systematic review that advance directives are completed with similar frequency by patients and presumably healthy adults suggests that this is an important area for improvement in future advance directive initiatives. While several particularly vulnerable populations—including people in nursing homes or hospice, older adults, and those with dementia and other neurologic diseases—do appear to have relatively high advance directive completion rates, approximately half of the members of these populations are still without any such directive, based on our review. These results also highlight a lack of evidence of advance directive completion among other vulnerable patient populations, such as those with chronic pulmonary and renal diseases, despite the high prevalence of those diseases^{51,52} and reports of suboptimal end-of-life care among patients who have them.^{53–55}

The participant demographic characteristics found in this review provide additional insight into specific populations to focus on in future advance directive initiatives. For example, most study populations consisted predominantly of elderly white females. Although the variable

methods used by individual studies to report advance directive completion rates preclude summary estimates of advance directive prevalence by specific demographic characteristics, it is clear that men, younger people, and Hispanics have been underrepresented in recent advance directive studies, relative to their proportions in the US census.

Conclusion

This systematic review presents the most comprehensive and robust evidence to date on the prevalence of advance directives in the United States and suggests that the prevalence is low and static. Because advance directives remain a key component of high-quality advance care planning, increasing their completion rates remains a national priority. Specifically, policies and interventions should focus on populations with low advance directive prevalence rates and at high risk for poor end-of-life care outcomes. Results of this review provide important baseline prevalence rates against which to measure future initiatives aimed at promoting adoption of advance directives among such populations. ■

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- 16 To access the Appendix, click on the Appendix link in the box to the right of the article online.
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