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## THE CARE SPAN

# Default Options In Advance Directives Influence How Patients Set Goals For End-Of-Life Care

**ABSTRACT** Although decisions regarding end-of-life care are personal and important, they may be influenced by the ways in which options are presented. To test this hypothesis, we randomly assigned 132 seriously ill patients to complete one of three types of advance directives. Two types had end-of-life care options already checked—a default choice—but one of these favored comfort-oriented care, and the other, life-extending care. The third type was a standard advance directive with no options checked. We found that most patients preferred comfort-oriented care, but the defaults influenced those choices. For example, 77 percent of patients in the comfort-oriented group retained that choice, while 43 percent of those in the life-extending group rejected the default choice and selected comfort-oriented care instead. Among the standard advance directive group, 61 percent of patients selected comfort-oriented care. Our findings suggest that patients may not hold deep-seated preferences regarding end-of-life care. The findings provide motivation for future research examining whether using default options in advance directives may improve important outcomes, including patients' receipt of wanted and unwanted services, resource use, survival, and quality of life.

**M**ost seriously ill patients value comfort and dignity over life extension,<sup>1</sup> but routine care often leads to treatment oriented toward extending life.<sup>2,3</sup> Deviating from this life-extending norm requires that someone actively request or suggest doing so.<sup>4-6</sup>

Specifying one's goals of care in the living will component of an advance directive provides patients with an opportunity to counter this tendency.<sup>7</sup> However, the text and structure of commonly used advance directives carry some of the same implicit biases that tend to favor life

extension in the absence of advance directives.<sup>2</sup> For example, in the widely used "Five Wishes" document,<sup>8</sup> the option "I want to have life support" is listed first in all three clinical scenarios, despite evidence that the ordering of choices influences the choices selected and that the one presented first often dominates.<sup>9,10</sup>

Federal law encourages people to complete advance directives,<sup>11</sup> and their use appears to be increasing.<sup>12</sup> Given the importance of the choices embedded in advance directives, it is essential to understand how the structure of advance directives affects patients' stated preferences. In studies providing hypothetical

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directives to college students<sup>13</sup> and elderly outpatients,<sup>14</sup> Laura Kressel and colleagues found that people were significantly more likely to indicate preferences to forgo life-sustaining interventions when completing advance directives in which forgoing these interventions was the default than when they had to actively choose to forgo the interventions.<sup>14</sup>

These findings using hypothetical scenarios raise the possibility that people might not have well-formulated, strongly held views on what forms of care at the end of life will best promote their values. Indeed, insights from behavioral economics suggest that preferences for end-of-life care are likely to be “constructed” at the moment people are asked to express them, rather than reflective of deeply ingrained preferences, because such choices are made infrequently and often without opportunity for feedback on whether the choices made promoted patients’ interests.<sup>2,15</sup> We tested this hypothesis by examining whether default options influence the choices of seriously ill patients in real advance directives, even after patients were alerted to the default option and their responses to it.

## Study Data And Methods

### DESIGN OVERVIEW, SETTING, AND PARTICIPANTS

We randomly assigned real advance directives, which differed only in their embedded default options, to outpatients who were at least fifty years old, lacked prior advance directives, had incurable diseases of the chest, and were not being considered for lung transplantation (Exhibit 1 and online Appendix Exhibit A).<sup>16</sup> Patients were recruited in the thoracic oncology and pulmonary outpatient clinics at the Hospital of the University of Pennsylvania from May 2010 through January 2012. The University of Pennsylvania Institutional Review Board approved this study.

Each week a research nurse screened electronic health records to identify eligible patients and obtained permission from these patients’ physicians to recruit them. The research nurse then met with potentially eligible patients in person, described the study, reviewed the potential benefits of completing advance directives, answered all questions, and provided patients with a written informed-consent document. The consent form and nurse’s spoken guidance

### EXHIBIT 1

Characteristics Of Patients In The Study To Assess The Affect Of Default Options In End-Of-Life Care Planning

Characteristic	Life-extension default (n=49)		Standard advance directive (n=43)		Comfort default (n=40)	
	Number	Percent	Number	Percent	Number	Percent
Age (mean years)	64.6	—	64.4	—	64.8	—
<b>SEX</b>						
Male	24	49.0	15	34.9	17	42.5
Female	25	51.0	28	65.1	23	57.5
<b>RACE</b>						
Black or African American	11	22.4	14	32.6	10	25.0
White or Caucasian	34	69.4	29	67.4	28	70.0
Other/unknown	4	8.2	0	0.0	2	5.0
<b>RELIGION</b>						
Catholic	12	24.5	10	23.3	12	30.0
Protestant	15	30.6	13	30.2	13	32.5
Other Christian	1	2.0	4	9.3	2	5.0
Jewish	2	4.1	3	7.0	1	2.5
Other faiths	13	26.5	10	23.3	6	15.0
Unaffiliated	6	12.2	3	7.0	6	15.0
<b>DIAGNOSIS</b>						
Non-small cell lung cancer/other thoracic malignancy <sup>a</sup>	18	36.7	16.9	37.2	13	32.5
Chronic obstructive pulmonary disease	14	28.6	15	34.9	14	35.0
Idiopathic pulmonary fibrosis	8	16.3	3	7.0	5	12.5
Other incurable fibrotic lung diseases	6	12.2	7	16.3	5	12.5
Other <sup>b</sup>	3	6.1	2	4.7	3	7.5

**SOURCE** Authors’ analysis. <sup>a</sup>Other thoracic malignancies include malignant pleural effusion (for example, from breast cancer) and mesothelioma. <sup>b</sup>Chronic obstructive asthma, bronchiectasis, cystic fibrosis, chronic pulmonary heart disease, other pulmonary insufficiency not elsewhere classified, other respiratory abnormalities, radiation pneumonitis, beryllium disease, lung involvement in systemic sclerosis, SLE (systemic lupus erythematosus), RA (rheumatoid arthritis).

informed patients that different types of advance directives would be assigned by chance, that patients in all groups could select or decline the same interventions and treatment goals, and that patients could change their choices at any time.

**INTERVENTIONS** Consenting patients were randomly assigned to complete one of three advance directives. All three were modified slightly from the professionally endorsed directive published by the Allegheny County Medical Society.<sup>17</sup> Each was deemed consistent with Pennsylvania law by the University of Pennsylvania Office of the General Counsel. Each included an identical section for the designation of a durable power of attorney for health care and a living will section that was altered among the three versions, as described below. Facsimiles of all of the advance directive forms used in this study can be found in the online Appendix.<sup>16</sup>

In all versions, patients were shown the exact same options. The versions differed in whether or not they contained a default—that is, whether a particular option was already marked with an X. When such a preselected default was used, that choice was placed first of the three options. Patients first were asked to choose an overall plan of care that prioritized extending life or one that prioritized minimization of pain and suffering.

The precise language used was adapted from that used by William Knaus in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a landmark clinical trial.<sup>18</sup> Patients could expand upon or clarify their choices by writing in the additional space provided.

Patients also were asked to choose whether or not they wished to receive five potentially life-sustaining interventions, such as feeding tube insertion, if they became unable to make decisions themselves. Again, patients could opt not to make these choices, and they could expand upon their choices in the additional space provided.

Allocation of individual patients was determined by electronic number generation, with assignment probabilities of 33.3 percent to each group. The research nurse recruiting patients used a numbered packet containing the assigned advance directive for each sequentially randomized patient.

One-third of patients were assigned to receive a “comfort default advance directive” that defaulted to the goal of relief of pain and suffering and nonreceipt of life-sustaining interventions. Patients were instructed to make other choices if they preferred by crossing out the default options and initialing lines next to their selections.

Another one-third of patients, in the “life-extension default advance directive” group, received a directive that defaulted to the goal of life extension and receipt of potentially life-sustaining interventions. Again, patients were shown how to make alternative selections.

Patients in a third group were assigned to receive a “standard advance directive” that required patients to actively choose their goals of care or preferences for specific interventions. As in usual practice, if patients did not make active choices, surrogates and clinicians would make decisions if patients lost capacity.

All patients were encouraged to involve their family members and physicians in completing their advance directives and to return them. If completed directives were not returned within ten days, the nurse telephoned patients up to three times to remind them and, if desired, to schedule a clinic visit specifically for help in completing the advance directive. For an advance directive to be considered complete, the signatures of two witnesses or a notary were required, as per Pennsylvania law.

**DEBRIEFING** After patients returned completed advance directives, one investigator called patients to debrief<sup>19</sup> them about the precise differences between their assigned advance directive and the advance directives that other study participants received. The investigator used an Institutional Review Board–approved debriefing script.<sup>16</sup> After explaining the goals of the study, including the concept of default options, the investigator read patients’ choices back to them and asked if they wished to make any changes.

**OUTCOMES** The primary outcome was the proportion of patients across the three intervention groups who selected a comfort-oriented goal of care. Given the propensity of the health care system to try to extend life in the absence of a directive otherwise,<sup>3,4,7</sup> patients who selected a life-extending goal of care and those who did not select an overall goal of care were jointly considered to have not selected a comfort-oriented goal.

We also assessed patients’ satisfaction with their advance care planning two months after the debriefing. One of two authors blinded to patients’ group assignments contacted patients by phone and administered the Canadian Healthcare Evaluation Project (CANHELP) questionnaire. This thirteen-item questionnaire has been validated for assessing satisfaction with end-of-life care planning.<sup>20,21</sup>

**STATISTICAL ANALYSIS** Our protocol specified a primary analysis in which we included only patients who returned completed advance directives. This analysis assessed the efficacy of

default options in advance directives among patients who completed them.

Because such analyses are susceptible to selection effects, intention-to-treat analyses were also conducted in which all patients who were randomly assigned an advance directive were included in the analyses. These intention-to-treat analyses were considered secondary because they are heavily biased toward the null. Specifically, they make the implausible assumption that all patients who did not complete advanced directives chose not to receive comfort-oriented plans of care and chose not to forgo any potentially life-sustaining interventions.

Chi-square tests, Cochran-Armitage tests of trend, and *t* tests were used as appropriate for two-group binary, three-group binary, and continuous outcomes data, respectively. In secondary analyses, logistic regression models were created to adjust for chance imbalance across arms in patient-level variables.

The clinic where patients were recruited for the study was modeled as a random effect to adjust for potentially correlated outcomes within clinics and to prevent confounding by clinic.<sup>22</sup> Analyses were performed using the software Stata, version 11.0, except for the Cochran-Armitage tests, which were performed using SAS, version 9.3.

We targeted a sample size of ninety-three patients. If evenly distributed across the three ordered groups, this sample would yield 81 percent power to declare significance at  $p = 0.05$  for a difference in the proportion of patients selecting comfort-oriented goals of care of 35 percent. This calculation assumed that the proportion in the standard advance directive group (the middle group) would be roughly equidistant between the proportions in the life-extension and comfort default groups.

**LIMITATIONS** This study was designed to enroll a relatively small number of patients from a single health system. Although it was a randomized trial, the sample size does not allow us to rule out the possibility that results were confounded by unmeasured variables, such as how well patients understood their illnesses or how often they spoke with their physicians about prognosis.

Second, we did not randomly assign the ordering of options within the standard advance directive but instead listed the comfort-oriented goal of care and the options to forgo specific interventions first for all patients in that arm. Because the first-listed option tends to be more commonly selected,<sup>9,10</sup> the observed differences in selections between the comfort-default advance directive and standard advance directive may actually underestimate the magnitude of the default effect.

Third, we enrolled only patients with serious thoracic diseases—primarily lung cancer and obstructive and restrictive lung diseases. The findings from this group of patients might not be generalizable to all patients or to patients with other specified health conditions.

## Study Results

One thousand and seventy-nine patients were screened and determined to be eligible for this study based upon reviews of their electronic health records. Of these, physicians requested that 43 not be contacted for study enrollment at the time of their visit, and 332 missed or rescheduled their visit or were not approached by the research nurse because of scheduling conflicts. Of the remaining 704 patients, 391 (55.5 percent) were deemed ineligible when in-person questioning revealed that they had existing advance directives.<sup>16</sup> Thus, there were 313 fully eligible patients, 132 (42.2 percent) of whom consented to participate.

One patient was excluded because he completely rewrote the assigned advance directive, making choices that were not classifiable using our coding scheme. The other 131 consented patients were included in intention-to-treat analyses.

Completed advance directives were returned by ninety-five patients (72.0 percent), only two of whom (2.1 percent) elected to reconsider their choices during the debriefing. One of these patients returned a new advance directive in which the only change was his selection of a new durable power of attorney; the other patient did not return a completed advance directive by the end of the study. Thus, ninety-four patients were included in per protocol analyses. Principal diagnoses and demographic characteristics among the 132 patients who consented to participate are shown in Exhibit 1.

**GOALS OF CARE** The specific goals selected by patients in each group are shown in online Appendix Exhibit F.<sup>16</sup> This exhibit shows that fifty-four (57.4 percent) of the ninety-four patients who returned a completed advance directive made a choice regarding their overall goals that differed from the default option.

Nonetheless, in per protocol analyses, advance directive default options significantly influenced the proportions of patients who chose comfort-oriented goals of care. Among the comfort default group, 77 percent retained comfort as their overall goal of care; 61 percent in the standard advance directive group chose comfort as their goal; and 43 percent of those in the life-extension default group rejected the default choice and indicated comfort as their primary

goal ( $p < 0.01$  for test of trend; Exhibit 2).

Intention-to-treat analyses produced a similar trend in proportions: 50 percent in the comfort default group, 47 percent in the standard advance directive group, and 31 percent in the life-extension default group ( $p = 0.04$ ).<sup>16</sup>

In secondary analyses adjusting for race, sex, age, marital status, and the recruiting research nurse, group assignment remained significantly associated with selections of comfort-oriented goals of care in per-protocol analyses (odds ratio: 2.12; 95% confidence interval: 1.21–3.72;  $p < 0.01$ ). Intention-to-treat analyses yielded similar but nonsignificant results (odds ratio: 1.51; 95% confidence interval: 0.96–2.37;  $p = 0.07$ ). These results were robust to different modeling strategies.<sup>16</sup>

Among the thirty-six patients in whom education level was measured, patients who had never attended college (10/17, 59 percent) were as likely as patients who had attended college (10/19, 53 percent) to make selections other than the default option (odds ratio: 1.33; 95% confidence interval: 0.26–6.68).

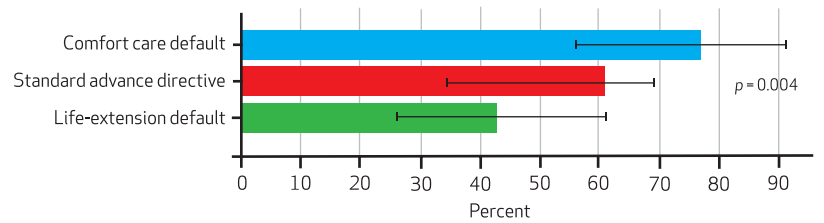
**CHOICES TO RECEIVE POTENTIALLY LIFE-SUSTAINING INTERVENTIONS** Patients completing different advance directive versions also had different probabilities of choosing to forgo potentially life-sustaining interventions. For example, the proportions of patients choosing to forgo feeding-tube insertion were 54 percent in the comfort-default group, 45 percent in the standard advance directive group, and 26 percent in the life-extension default group ( $p = 0.01$  for test of trend; Exhibit 3). For cardiopulmonary resuscitation, corresponding proportions were 42 percent, 32 percent, and 20 percent ( $p = 0.03$ ).

Similar but nonsignificant trends were noted for intensive care unit admission ( $p = 0.06$ ), mechanical ventilation ( $p = 0.06$ ), and hemodialysis ( $p = 0.08$ ). Similar trends were also noted in intention-to-treat analyses, although only the test for feeding-tube insertion was statistically significant.<sup>16</sup>

**SATISFACTION WITH END-OF-LIFE CARE PLANNING** Assessments of patients' satisfaction with end-of-life care planning were completed for seventy-eight of the ninety-four patients who completed advance directives (83.0 percent). Of the remaining sixteen patients, at least five died within two months; the remainder were lost to follow-up, and it was not known with certainty that they were still living. Global and average satisfaction scores were high across the three intervention groups (greater than 4.5 out of a possible 5) and no significant between- or among-group differences were identified.<sup>16</sup>

**EXHIBIT 2**

**Percentage Of Patients Choosing A Comfort-Oriented Goal Of Care (Per Protocol Population)**



**SOURCE** Authors' analysis. **NOTES** Standard error bars denote 95% confidence intervals.

**Discussion**

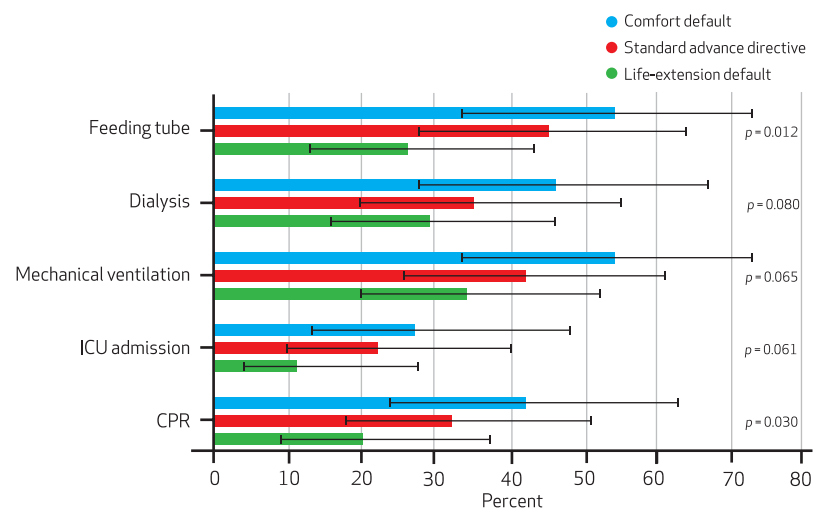
Default options, or the events or conditions that will be set into place if no alternative is actively chosen,<sup>23,24</sup> have been shown to influence decisions in domains as diverse as drivers' insurance,<sup>25</sup> retirement savings,<sup>26,27</sup> influenza vaccination,<sup>28</sup> and organ donation.<sup>29,30</sup> A hallmark of defaults is that they lead gently, without restricting any options.

Thus, when people have strong preferences, such as for low-deductible health care insurance, they commonly make choices that counter the default. This is precisely what happened, for example, with the roll-out of Medicare Part D drug coverage, when despite the default annual deductible of \$250, most Americans chose plans with no deductible at all.<sup>24</sup>

The study on which we report here shows that default options have large influences on

**EXHIBIT 3**

**Percentage Of Patients Choosing To Forgo Each Intervention, By Type Of Advance Directive (Per Protocol Population)**



**SOURCE** Authors' analysis. **NOTES** Standard error bars denote 95% confidence intervals. CPR is cardiopulmonary resuscitation.

seriously ill patients' actual choices for health care interventions at the end of life. Overall, most patients with terminal illnesses stated preferences for comfort-oriented care when offered the opportunity to state these preferences in real advance directives, but the proportions of patients choosing this option differed markedly as a function of how the default was set.

Importantly, these effects manifested even after patients were made aware of the defaults and shown how they had responded to them, and after it was made easy to choose counter to the default, which many patients did, particularly in the life-extension default and standard advance directive groups.<sup>16</sup> Only 2.1 percent of patients in this study elected to reconsider their selections after being alerted to the manipulation of the default option, but ultimately these patients did not change their original selections. Furthermore, intentionally setting defaults was not associated with any changes in patients' satisfaction with their choices, which suggests that patients were content to be guided in such decisions.

Although one might expect patients to hold strong prior preferences about end-of-life treatments, the findings that people were heavily swayed by defaults, and content to be swayed, suggest that many seriously ill patients lack deep-seated preferences about their end-of-life care. Despite the importance of end-of-life health care decisions, it should come as no surprise that many patients lack well-established preferences in this domain. People commonly lack prior preferences for decisions that are made infrequently and provide few opportunities for learning after the fact whether the choices made did or did not promote their goals.<sup>15</sup> These are precisely the characteristics of end-of-life care choices.

The power of defaults in determining stated end-of-life care preferences underlines the importance of selecting defaults carefully without limiting patients' options.<sup>24,31</sup> At the same time, clinicians should recognize that it is often difficult to avoid defaults, and they should therefore consider carefully the predictable consequences of which defaults are used or allowed to remain.<sup>2,24,32</sup>

Indeed, there is a default option embedded in the standard approach to advance care planning: If patients do not actively choose specific goals in advance directives, clinicians and surrogates must make decisions for patients who lose capacity. Because many patients do not complete advance directives or merely designate a durable power of attorney, this "default to surrogate decision making" not only is prevalent, but also carries important bereavement consequences for family members.<sup>33-35</sup>

Given that most patients place a high priority on not burdening their loved ones<sup>35-39</sup> and that most patients in our study selected comfort-oriented goals even in the standard advance directive group, there is reason to believe that the current systemic default of life extension might not optimally promote patients' wishes and values.

These results can also be interpreted as evidence that advance directive forms, absent a well-structured conversation among patients, family members, and providers, will not meaningfully promote patients' values.<sup>40</sup> A preferable approach to advance care planning may be one that relies not on forms but on carefully structured conversations that explore patients' values in the presence of their potential surrogate decision makers.<sup>41</sup>

For particular patients and families cared for by particular clinicians—for example, patients with good access to physicians well trained in end-of-life communication and with family members experienced in advance care planning—such coordinated communication may indeed prove optimal. But it is uncertain whether this approach could be implemented across diverse populations with differential access to skilled clinicians and experienced family members.

By contrast, designing an advance directive that would help the majority of patients make decisions that promote their goals could provide a way to improve end-of-life care more broadly, for all Americans. Recent evidence provides substantial motivation to try, as observational studies in the United States show that patients who complete advance directives less commonly die in a hospital,<sup>12,42-44</sup> more often receive care consistent with their preferences,<sup>12</sup> have surrogates who are less likely to report concerns with communication near the end of life,<sup>43</sup> and, in certain regions, receive less costly care.<sup>44</sup>

This study shows that using default options in advance directives strongly influences the end-of-life care choices that people make without affecting their satisfaction with their advance care planning. Furthermore, because the effects of defaults were identical even after patients were directly told about the default, this study suggests that for many patients, "preferences" for end-of-life care are not deeply held.

This study also provides motivation for future research examining whether using default options in advance directives may improve important outcomes, including patients' receipt of wanted and unwanted services, survival, quality of life, resource use, and family members' bereavement. If such research shows that setting defaults in advance directives improves such

outcomes while adhering to ethical standards for default setting (including assurances that patients are aware of the decisions to be made and that countering the default can be done

easily),<sup>3,24,45,46</sup> then the clinical use of default options in advance directives may provide a novel way to improve end-of-life care for large populations of seriously ill patients. ■

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In this month's *Health Affairs*, Scott Halpern and coauthors report on their study testing whether end-of-life care decisions are influenced by the ways in which options are presented. They randomly assigned 132 seriously ill patients to complete one of three types of advance directives that had either different “default” choices already selected for comfort-oriented care or life-extending care, or no options checked at all. The results indicated that the defaults clearly influenced patients' choices and that patients might not hold deep-seated preferences regarding end-

of-life care, the authors write. The authors recommend further research to determine whether use of advance directives with these default options leads to outcomes important to patients, families, and society.

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