Default Options and their Effect on Patients’ Advance Directives

Danielle Bendicksen

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Abstract

**Background:** Advance directives (ADs) are a way for patients to state their wishes for care in the case that they are unable to express them. Within the US healthcare system, in the absence of ADs or other legal orders, the default is often to sustain life until no longer medically possible. This systematic review analyzes studies that seek to learn how patients >50 years old make decisions for their care on ADs and if default options on the AD form itself could affect their choices.

**Methods:** Exhaustive search of MEDLINE-PubMed, CINAHL, and Web of Science, using the terms “advance directive” and “default.” Relevant studies were assessed for quality using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) tool.

**Results:** Two randomized control trials met eligibility criteria. One trial randomly assigned 3 versions of real ADs to seriously ill patients >50 years old. One trial version had a comfort-care default, the other trial had a life-extending care default, and the third was a standard AD control without default options. The other trial randomly assigned 3 versions of surveys about ADs to patients >65 years old. The 3 groups were similar, with an implicit comfort-care default, an implicit life-extension default, and a control without a default. Both studies found that default options affected the way that patients made choices for end-of-life care.

**Conclusion:** Patients’ decisions for end-of-life care may be affected by default options. Providers, healthcare systems, and states must be aware of this phenomenon when structuring forms and conversations around this subject.

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Default Options and their Effect on Patients’ Advance Directives

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A Clinical Graduate Project Submitted to the Faculty of the
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Clinical Graduate Project Coordinator: Annjanette Sommers, PA-C, MS
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Keywords: Advance directive, default
Table of Contents
Abstract ................................................................. Error! Bookmark not defined.
Table of Contents .......................................................... 3
List of Tables ................................................................. 3
List of Abbreviations ......................................................... 3
BACKGROUND .................................................................. 4
METHODS ...................................................................... 6
RESULTS .......................................................................... 6
DISCUSSION .................................................................... 9
CONCLUSION ..................................................................... 13
REFERENCES ................................................................. 14

List of Tables
Table 1: Quality Assessment of Reviewed Studies

List of Abbreviations
AD  Advance Directive
POLST  Physician Order for Life-Sustaining Treatment
CPR  Cardiopulmonary resuscitation
ICU  Intensive Care Unit
RCT  Randomized control trial
Default Options and their Effect on Patients’ Advanced Directives

BACKGROUND

The choices patients make in advance directives (ADs) are intended to delineate some of the most important preferences that they have for their healthcare. ADs state wishes for care in various scenarios in which patients may not be able to verbalize their choices. For example, ADs allow adults to decide the level of care they would like to receive should they be deemed to be in a permanently unconscious state. ADs in the US vary between states, but they also allow patients to designate a legal healthcare representative to make decisions for them in the case that they are not able to do so.

ADs are often confused with Physician Order for Life-Sustaining Treatment (POLST) forms¹, which are different state-specific medical forms. The POLST is an order signed by a healthcare provider to withhold or provide certain treatments in all cases. For example, POLST is a clinician order to provide comfort measures only, limited treatment, or the full scope of medical treatment regardless of the scenario.¹

One of the most important issues that both ADs and POLSTs attempt to tackle is giving patients’ agency in what they want their end-of-life medical care to look like. Most people prefer to die at home², but these wishes are in stark contrast to reality and the status quo of the United States healthcare system. Only about 30-35% of Medicare patients die at
home, while over 50% die in either acute care hospitals or nursing homes. Additionally, most patients with terminal conditions prefer comfort-only care to life-sustaining care. In contrast to the preferences of many patients, the default of the US healthcare system is to sustain life. In the absence of explicit instructions to discontinue life-sustaining care, many patients receive invasive, costly care to prolong their lives.

Another issue is healthcare costs to both patients and the system as a whole. In 2011, $205 billion was spent on US individuals in their last year of life, equaling 13% of total healthcare expenditures. Focusing on comfort measures and quality of life rather than life-sustaining treatment for patients in their last year of life may reduce healthcare costs. This focus, however, brings up an ethical question: should cost even be mentioned when discussing life and death decisions?

Due to the contrast between what many patients want and what actually happens within the healthcare system, further study into advance directives and how to improve them is vital to helping better patients’ outcomes according to their wishes. Understanding more about the psychology behind how patients make certain choices in the advance care planning documents could help direct how states and healthcare systems tailor these documents to specific patient groups in the future. This systematic review analyzes studies that investigated whether default
settings on advance directive forms affected the way that patients over 50 years old choose options for end-of-life care.

**METHODS**

An exhaustive literature search of MEDLINE-PubMed, Web of Science, and the Cumulative Index of Nursing and Allied Health Literature (CINHAL) was conducted using the search terms “advance directive” and “default.” Randomized control trials (RCTs) published in the English language within the last 10 years were included. Participants in the studies must be over 50 years old to be included in this analysis. Papers meeting inclusion criteria were assessed using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) tool.⁷

**RESULTS**

The search of available medical literature resulted in 28 potential papers across the 3 databases, with 3 completed RCTs. One RCT⁸ was excluded that met all eligibility criteria except participant age as the study included only college-aged students. One protocol was published for an ongoing RCT.⁹ This protocol was excluded, as results have not been published yet; however, it should be included in future analyses. Two studies¹⁰,¹¹ met all eligibility criteria and were included in this analysis.

**Default Options in Advance Directives Influence How Patients Set Goals for End-of-Life Care (Halpern et al 2013)**
Halpern and colleagues\textsuperscript{10} randomly assigned 3 types of real advance directives (ADs) to patients >50 years old with incurable diseases of the chest. The first type of AD had a default option of comfort-care only, the second had a default option of life-sustaining care, and the third was a control group that was given a standard AD without default options. After completing the ADs, patients were debriefed about the purpose of the study and asked if they would like to change their options.

The authors performed a per-protocol analysis of a total of 132 patients’ ADs (life-extension default n=49; comfort-care default n=40; no default n=43) without significant demographic differences between the 3 study groups. While patients were overall more likely to choose comfort-only care, default options significantly affected their choices (p<0.01). Seventy-seven percent in the comfort-care default maintained that choice, while 43% in the life-extension default rejected that option for comfort-care. Sixty-one percent of patients in the no default group opted for comfort-care. Halpern and colleagues\textsuperscript{10} also performed intention-to-treat analyses, including all randomized participants regardless if they returned completed ADs. This analysis resulted in a similar trend, but without statistically significant results (p=0.07).

The authors also found significant differences using per-protocol analyses between the groups in preferences concerning feeding tube insertion (p=0.012) and cardiopulmonary resuscitation (p=0.030).
Analogous but non-significant differences were assessed in preferences for dialysis (p=0.080), mechanical ventilation (p=0.065), and ICU admission (p=0.061). The paper also found that the overwhelming majority of patients retained their choices even after they were debriefed as to the study’s purpose and default options.

The article \textsuperscript{10} asserts that the defaults “lead gently, without restricting any options.” The authors also suggest that these results suggest that patients may not hold strong preferences on end-of-life care. Halpern and colleagues suggest that we must be very careful when choosing default options in ADs.

\textbf{The Influence of Default Options on the Expression of End-Of-Life Treatment Preferences in Advance Directives (Kressel et al 2007)}

This randomized control trial\textsuperscript{11} sent 3 versions of questionnaires about ADs to internal medicine general outpatients who were >65 years old at an academic hospital. The first version was dubbed the “withhold condition,” as participants checked off treatments they wished to be withheld in the event that they became permanently unconscious. As any treatment not checked would be provided, the withhold condition was analogous to a life-sustaining default. In the “provide condition,” participants checked off treatments they wished to be administered in the event that they became permanently unconscious. The “provide condition” is analogous to a comfort-care default as participants had to actively choose treatments that they wanted and
could passively default to no life-sustaining treatment. The third condition was a control without an implied default. It forced patients to delineate which treatments they wanted provided and withheld.

Participants did not differ across demographic characteristics, but the authors did find a response trend based on age; younger participants were significantly more likely to respond than older participants (p=0.003). Participants chose life-sustaining care 28% of the time in the no default control condition, 38% in the life-sustaining default condition, and 20% of the time in the comfort-care default condition (p=0.03). Pairwise comparisons demonstrated that the two implied default conditions significantly differed from each other, but neither default differed significantly from the no default control.

Kressel and colleagues additionally compared participants’ responses in several specific instances. The authors found significant differences between the default groups in participants’ preferences in the following cases: terminal illness; treatment that is experimental, futile, or that will merely prolong imminent dying; artificially provided fluids; intubation; being unable to recognize loved ones; being unable to care for oneself (bathing, dressing, or eating).

**DISCUSSION**

While both studies were RCTs with relatively conclusive results, aspects of each study had significant limitations. Halpern and colleagues
studied seriously ill patients with diseases of the chest. While the sample was relatively homogenous in prognosis, patients’ understanding of their condition and prognosis may have varied greatly. The homogeneity of the sample may also make the study less generalizable.

Kressel and colleagues suffered from an almost opposite problem: their sample included patients with various prognoses and conditions. This study also suffered from using a survey about ADs rather than real ADs. Kressel and colleagues additionally stated that there was an age effect in survey response rates: younger patients were significantly more likely to respond than older patients.

While the Halpern et al study addressed patient satisfaction with the AD process, neither study examined any patient-important outcomes such as cost, satisfaction with care, admission rate, admissions, and compliance with AD choices. All of these actual outcomes not studied are more important than patient’s choices on a form.

Future studies should measure these long term and patient- and healthcare system-important outcomes in context with default choices on ADs. Gabler and colleagues recently published a protocol for an ongoing trial to test ADs with comfort-care defaults on seriously ill patients and then measure outcomes such as admissions, concordance of preferences and actual care received, bereavement outcomes, costs of care, and hospice
usage. This study will lend more credence to, if, and how default options affect patients’ healthcare and costs.

The results of both studies\textsuperscript{10,11} show that default options have the potential to affect the way people make end-of-life care decisions. Two of the authors of the Kressel et al study\textsuperscript{11} also found a similar default effect when sending questionnaires about end-of-life decisions to college students, suggesting that older adults are not the only people susceptible to this phenomenon.

Halpern and colleagues\textsuperscript{10} suggest that this “default effect” may be due to the fact that patients do not have strong preferences about end-of-life care. This effect may, however, be a bit more complicated. No one knows for certain what the best way to die is or exactly what one’s preferences will be until she/he is in that very situation. This uncertainty may influence patients to pick what is most normative, or the default. People’s attitudes and behaviors may be modified based on guidance from authority figures.\textsuperscript{12} Patients may perceive the wording on an AD as a suggestion from an authority figure that the default option is the best or most normative choice.

Providers should recognize this phenomenon when discussing end-of-life options with their patients. States and healthcare systems alike need to be aware of this psychology when formulating their ADs and policies surrounding end-of-life care. The influence of default options also begs the
question of whether it is ethical to lead patients in a particular direction when making such impactful decisions.

At the same time, it may be unavoidable to influence patients’ choices in one way or another. In other situations, research has shown that the first option listed is chosen the most often.\textsuperscript{13} Many advance directive forms, including the standard form in the state of Oregon\textsuperscript{14}, list life-sustaining measures first. Halpern and colleagues\textsuperscript{10} even noted that they did not randomize the order of choices on the control group’s ADs. The study suggested that consistently listing life-sustaining options first might underestimate the default effect. All of these factors may necessitate that the US healthcare system and government re-examine its implicit defaults in end-of-life care to align them with the wishes of older adults.

Even more importantly than advance directives and the implications of these forms, we need to think about end-of-life conversations as a whole. Oftentimes these conversations between providers and patients about end-of-life care don’t even happen.\textsuperscript{15} Eighty percent of patients in surveyed in California want to talk with their providers about end-of-life care, but only 7\% actually had that conversation.\textsuperscript{15} Only thirty-eight percent of Californians even heard of an AD.\textsuperscript{15} Without these conversations and forms such as ADs and POLST, decisions about what to do in these situations must be made in the moment and possibly when the patient is not able to take part in the conversation.
CONCLUSION

These studies have strongly suggested that patients’ decisions regarding end-of-life care may be affected by default options on their advance directives. More research on patient-important outcomes and costs to the individual and healthcare system are underway. Now that this effect has been tested, the healthcare system and state governments must decide if and how to ethically utilize it. It is also important that providers prioritize these conversations for patients and insure that they are aware of their options before they are in a potentially emergent situation.

Our healthcare system and culture’s “default” is to sustain life, while most seriously ill patients wish for comfort-care rather than life-extension.\textsuperscript{4} Could restructuring advance directives to suggest a more comfort-oriented goal rather than extending life help resolve this discord and if so, is it ethical to do so? Advance directives play only a small role in conversations surrounding end-of-life care, but these studies illustrate the power of suggestion in patients’ choices. Providers, healthcare systems, and states must be aware of this phenomenon when structuring forms and conversations around end-of-life care.
REFERENCES

Table 1: Quality Assessment of Reviewed Articles

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Downgrade Criteria</th>
<th>Upgrade Criteria</th>
<th>Quality</th>
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<tbody>
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<td></td>
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<td>Limitations</td>
<td>Indirectness</td>
<td>Inconsistency</td>
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<td>Halpern et al10</td>
<td>RCT</td>
<td>Serious&lt;sup&gt;a,b&lt;/sup&gt;</td>
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<tr>
<td>Kressel et al11</td>
<td>RCT</td>
<td>Serious&lt;sup&gt;a,d&lt;/sup&gt;</td>
<td>Serious&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Not Serious</td>
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<sup>a</sup> Blinding was not relevant or possible in these studies and they were not downgraded for lack of blinding
<sup>b</sup> Halpern did not randomize the order of choices on the standard AD, always listing life-sustaining measures first, despite evidence that the first option listed is the most commonly selected.<sup>13</sup>
<sup>c</sup> Halpern study authored by director of the Fostering Improvement in End-of-Life Decision Science Program; positive results could directly benefit author’s program
<sup>d</sup> Kressel study reported attrition bias related to the survey response rate. Response rate for survey was associated with age; younger participants were more likely to return the survey (p=0.003).
<sup>e</sup> Kressel study measured participants’ responses on a survey, rather than a legal advance directive (AD) as in the Halpern study.