Difficult End-of-Life Treatment Decisions

Do Other Factors Trump Advance Directives?

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Background: Advance directives are widely promoted as a means to plan for patients’ decisional incapacity, yet there is little evidence of their effectiveness. We devised a study to assess physicians’ compliance with hypothetical advance directives and further examine their clinical reasoning.

Methods: The study consisted of an analysis of a mailed written survey containing 6 hypothetical cases of seriously ill patients. Each case contained an explicit advance directive with potential conflict between the directive and (1) prognosis, (2) wishes of family or friends, or (3) quality of life. Data were collected on the clinical treatment decisions made by physicians and the reasons for those decisions. Study participants were all internal medicine faculty and resident physicians from a single academic institution.

Results: A total of 47% analyzable surveys (117/250) were returned. Decisions by faculty and residents were not consistent with the advance directive in 65% of cases. This inconsistency was similar for faculty and residents (68% and 61%, respectively; P > .05). When physicians made decisions inconsistent with the advance directive, they were more likely to list reasons other than the directive for their decisions (89%; P < .001).

Conclusions: Internists frequently made treatment decisions that were not consistent with an explicit advance directive. In difficult clinical situations, internists appear to consider other factors such as prognosis, perceived quality of life, and the wishes of family or friends as more determinative than the directive. Future work needs to explore the generalizability of these findings and examine how strictly patients desire their advance directives to be followed.

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Significant concern remains about how well physicians know and follow the treatment preferences of their patients. Decisions are particularly problematic for critically ill and dying patients who lose their capacity to make medical decisions. A variety of factors may influence the treatment decisions made for incompetent patients. Physicians may use the probability of survival or recovery in recommending particular treatments. Perceived quality of life can also influence physicians and families. In an attempt to facilitate this process, advance directives were created to allow patients to plan treatment decisions in the event of decisional incapacity.

While advance directives have been widely promoted as a means to ensure that patients’ treatment preferences were followed, there is limited evidence that they actually accomplish this purpose. Several studies have found that advance directives have little effect on the decisions physicians make. Physicians are frequently unaware of the existence of their patient’s advance directive, and knowledge of the existence of a directive does not ensure that it will be followed.

Physician characteristics such as age, specialty, race, and sex have been associated with differences in clinical decision making. For example, Hinkka and colleagues found that oncologists as a group were more willing to forgo treatments. A nationwide survey of physicians found that white physicians were more likely to consider physician-assisted suicide acceptable than black physicians, and that they would also be more likely to decline aggressive treatments for themselves. This same study found that while older physicians were more likely to prepare an advance directive for themselves, they expressed more skepticism about the advance care planning process than did younger physicians.

Should advance directives always be followed explicitly? Are there, at times,
A 48-year-old woman with type 1 diabetes mellitus is receiving dialysis. She has had a stroke and is now completely aphasic. The neurologists believe that there is a poor prognosis for much recovery.

Advance Directive: She requests full treatment regardless of prognosis and names her husband as proxy. However, he requests that dialysis be stopped.

Respondent treatment choices: Stop dialysis or continue dialysis?

1. Stop dialysis
2. Continue dialysis

The main reason for my treatment decision is (check only one box):

1. Advance directives take priority
2. Families/friends take priority
3. Likelihood of survival takes priority
4. Quality of life takes priority

We conducted a survey to assess how internal medicine attending and resident physicians approach advance directives. Using conflicted, end-of-life clinical scenarios, we examined how physicians would respond to an explicit advance directive.

**METHODS**

We created a survey containing 6 hypothetical cases. Each case described a patient with a serious or life-threatening illness who had lost his/her decision-making capacity. Contained within each case was an explicit advance directive stating the patient’s treatment preferences. In some of the cases the advance directives also noted a proxy appointment. An example of these cases is shown in **Figure 1**.

The cases were designed to illustrate a conflict between the patients' preferences as stated in the advance directive and the context of the clinical situation (ie, medical prognosis, family desires, and/or perceived quality of life). Respondents were then asked to opt for an aggressive or nonaggressive treatment. In addition, they were asked to explain the rationale for their decisions. In close-ended options, respondents could cite “advance directive,” “quality of life,” “family or friend,” or “prognosis” as the primary reason for their treatment choice. They were also given space to write other comments. The survey instrument was pilot-tested for clarity, validity, and content.

A convenience sample of faculty and residents at the department of Internal Medicine of Loma Linda University Medical Center and affiliated hospitals (Jerry L. Pettis Memorial Veterans Affairs and Riverside County Regional Medical Centers) was surveyed. A second mailing was sent to nonresponders. The study was reviewed and approved by the human study subcommittees of the sponsoring institutions.

Statistical methods include the t test for means and the χ² test for categorical variables. Sample size estimates are problematic, given the exploratory nature of the study and the fixed number of available physicians.

Of the 250 surveys mailed, a total of 117 analyzable surveys (47%) were returned from 77 faculty and 40 resident internal medicine physicians. Three additional returned surveys were not analyzed because they did not indicate faculty or resident status. **Table 1** presents the basic demographics of the 2 groups.

Overall, treatment decisions by faculty and residents were not consistent with the advance directive in 65% of cases (**Figure 2**). Despite the presence of an explicit advance directive in each hypothetical case, respondents frequently chose treatment decisions different from the stated advance directive choice made by the patient. While these treatment decisions varied among the cases, the responses of faculty and resident physicians were similar in the frequency of inconsistency with the advance directive (faculty, 68% vs resident, 61%; P > .05). **Figure 2** shows the aggregate physician responses for each case.

Overall, the advance directive was cited as determinative in less than half of the cases (37% for all physicians). Residents were more likely to cite an advance directive as the reason for the treatment decision, while faculty were more likely to cite quality of life as determinative (**Table 2**). Not surprisingly, when physicians made decisions inconsistent with the advance directive, they were likely to list other reasons for their choices (89%; P < .001). Conversely, in decisions consistent with the stated ad-

**Table 1. Characteristics of Survey Respondents**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Faculty (n = 77)</th>
<th>Residents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response to mailed survey, %</td>
<td>50</td>
<td>41</td>
</tr>
<tr>
<td>Age, mean (range), y</td>
<td>48 (29-83)</td>
<td>30 (25-46)</td>
</tr>
<tr>
<td>Male sex, %</td>
<td>74</td>
<td>63</td>
</tr>
<tr>
<td>Nonwhite, %</td>
<td>32</td>
<td>78</td>
</tr>
<tr>
<td>Postgraduate training, No. of residents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year 1</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Year 2</td>
<td>13</td>
<td></td>
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<td>Year 3</td>
<td>10</td>
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<td>Year 4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Year 5</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 2.** Treatment decisions not consistent with the patient’s advance directive, given as percentage of physicians.

Good reasons for choosing differently from what a patient had previously indicated? Significant changes in a patient’s clinical status can influence physicians and surrogate decision makers. Furthermore, patients may be willing to allow a certain amount of latitude in their surrogates’ decision making. Thus, they may recognize the impossibility of predicting every contingency.

We conducted a survey to assess how internal medicine attending and resident physicians approach advance directives. Using conflicted, end-of-life clinical scenarios, we examined how physicians would respond to an explicit advance directive.
Despite the presence of an explicit advance directive, physicians frequently made treatment decisions contrary to documented patient preferences. Further, we found that faculty and resident physicians generally made similar choices in treatments. Thus, the level of training and experience did not appear to affect treatment choices. In our study, physicians appeared to be influenced by more than 1 factor. While compelling, the advance directive may have been viewed as only part of the information needed to make treatment decisions. Quality of life, treatment outcomes, and family preferences were often more decisive for physicians. However, these other factors may reflect the physicians' values rather than those of the patient.12

The disparity between treatment preferences expressed in advance directives and the choices physicians indicate may also represent a profound gap in perceptions. Physicians, patients, and families may differ on what constitutes appropriate treatment or about acceptable health status. While assistance from an ethics committee, chaplain, or other ancillary service may facilitate conflict resolution, physicians must still make difficult decisions. We intentionally designed the study to force respondents to make a decision. It seems unlikely that advance directives as they are presently formulated are adequate to close this gap.

Our study has a number of limitations. First and most importantly, the survey is based on hypothetical cases. How physicians make decisions for actual patients in real time and with more information may be different. Second, the study was based at a single institution and conducted on a relatively small sample of respondents. As some respondents indicated, there can be genuine differences in opinion as to what constitutes “aggressive treatment.” For example, many physicians would consider radiation treatment for bone metastases a form of palliation. However, uncertainty will always exist and physicians and surrogates are still faced with the dilemma of interpreting how the patient views treatments. Finally, this study was done at an academic institution, it may be less reflective of the community clinical practice.

CONCLUSIONS

As they are presently configured, advance directives are poorly equipped to cope with complex and conflicted clinical situations. While potentially useful as guides to medical decisions, there are serious limitations to their usefulness. Our study provides some insight into how physicians make end-of-life treatment decisions. While advance directives are part of the decision-making process, physicians consider a variety of factors in making treatment decisions.

Despite the apparent lack of efficacy of advance directives, they can serve an important function. Advance directives have helped to encourage physicians and patients to start conversing about treatment decisions. However, the limitation of advance directives illustrates the need for more effective conflict resolution when patients, families, and staff disagree about treatment choices.13 Continuing improvement in the process of end-of-life decision making is needed. This process will have to recognize the inherent uncertainties in caring for seriously ill patients.

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REFERENCES


Table 2. Rationale for Treatment Decisions

<table>
<thead>
<tr>
<th>Reason Cited for Treatment Decision</th>
<th>Faculty, %</th>
<th>Residents, %</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance directive</td>
<td>32</td>
<td>45</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Family/friends</td>
<td>18</td>
<td>11</td>
<td>.09</td>
</tr>
<tr>
<td>Prognosis</td>
<td>18</td>
<td>20</td>
<td>.42</td>
</tr>
<tr>
<td>Quality of life</td>
<td>38</td>
<td>28</td>
<td>.005</td>
</tr>
</tbody>
</table>

*Percentages total more than 100 as some respondents indicated more than 1 reason for a particular decision.

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REFERENCES


Correction

Error in Acknowledgments. In the article by Hardin and Yusufaly titled “Difficult End-of-life Treatment Decisions: Do Other Factors Trump Advance Directives?” published in the July 26 issue of the ARCHIVES (2004;164:1531-1533), information about a previous presentation of the study was omitted. A paragraph in the acknowledgments should have read: This study was presented in poster form at the annual meeting of the Society of Internal Medicine; May 5-6, 2000; Boston, Mass.