Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults

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**IMPORTANCE** Hospitalized older adults often lack decisional capacity, but outside of the intensive care unit and end-of-life care settings, little is known about the frequency of decision making by family members or other surrogates or its implications for hospital care.

**OBJECTIVE** To describe the scope of surrogate decision making, the hospital course, and outcomes for older adults.

**DESIGN, SETTING, AND PARTICIPANTS** Prospective, observational study conducted in medicine and medical intensive care unit services of 2 hospitals in 1 Midwestern city in 1083 hospitalized older adults identified by their physicians as requiring major medical decisions.

**MAIN OUTCOMES AND MEASURES** Clinical characteristics, hospital outcomes, nature of major medical decisions, and surrogate involvement.

**RESULTS** According to physician reports, at 48 hours of hospitalization, 47.4% (95% CI, 44.4%-50.4%) of older adults required at least some surrogate involvement, including 23.0% (20.6%-25.6%) with all decisions made by a surrogate. Among patients who required a surrogate for at least 1 decision within 48 hours, 57.2% required decisions about life-sustaining care (mostly addressing code status), 48.6% about procedures and operations, and 46.9% about discharge planning. Patients who needed a surrogate experienced a more complex hospital course with greater use of ventilators (2.5% of patients who made decisions and 13.2% of patients who required any surrogate decisions; \( P < .001 \)), artificial nutrition (1.7% of patients and 14.4% of surrogates; \( P < .001 \)), and length of stay (median, 6 days for patients and 7 days for surrogates; \( P < .001 \)). They were more likely to be discharged to an extended-care facility (21.2% with patient decisions and 40.9% with surrogate decisions; \( P < .001 \)) and had higher hospital mortality (0.0% patients and 5.9% surrogates; \( P < .001 \)). Most surrogates were daughters (58.9%), sons (25.0%), or spouses (20.6%). Overall, only 7.4% had a living will and 25.0% had a health care representative document in the medical record.

**CONCLUSIONS AND RELEVANCE** Surrogate decision making occurs for nearly half of hospitalized older adults and includes both complete decision making by the surrogate and joint decision making by the patient and surrogate. Surrogates commonly face a broad range of decisions in the intensive care unit and the hospital ward setting. Hospital functions should be redesigned to account for the large and growing role of surrogates, supporting them as they make health care decisions.


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As the population ages, a greater number of hospitalized older adults will have impaired cognition due to a rising prevalence of Alzheimer disease, delirium, and other related disorders. Such patients often face major decisions about their medical care at a time when they cannot communicate their preferences or participate in decision making. Prior research examining hospitalized adult patients of all ages has shown that between 25% and 40% lacked the capacity to make medical decisions based on standardized assessment, and 1 study of hospitalized older adults report that 43% had some degree of cognitive impairment.

When patients cannot make decisions, clinicians turn to surrogate decision makers. The surrogate is most commonly a close family member who in some cases has been chosen by the patient as a health care power of attorney. The presence of a surrogate requires fundamental changes in the way that clinicians communicate and make decisions. Some evidence suggests that key decisions, such as writing do-not-resuscitate orders, may even be delayed when surrogates are required to make these decisions. Previous studies of decision-making capacity in the hospital have not examined how often surrogates are called on to make decisions or described the decisions encountered by surrogates.

Research on the topic of surrogate decision making has instead focused on surrogates’ accuracy in hypothetical situations regarding future decision making, identified the burdens and distress experienced by surrogates, and described surrogate perspectives on various aspects of decision making. However, most of this work has focused on decision making in the intensive care unit (ICU), the nursing home, or the setting of end-of-life care.

We were unable to identify previous studies that describe the scope of surrogate decision making as it actually occurs among hospitalized older adults, including the frequency of the decisions, the nature of the decisions, and the outcomes for the patients. To better understand these issues, we conducted a prospective, observational study of surrogate decision making for hospitalized adults 65 years and older. Data about the scope and magnitude of surrogate decision making for older adults can help us redesign hospital care to more effectively provide for the needs of aging patients and their families.

**Methods**

**Setting**

The study was conducted on the inpatient medicine and medical ICUs of 2 hospitals in a Midwestern city. The first was a university-affiliated, 316-bed urban, public hospital with more than 15 000 admissions per year. The second was a 1462-bed, university-affiliated tertiary care referral center with more than 58 000 admissions per year. Both hospitals are staffed by medical school faculty and train fellows, residents, and students. The study was approved by the Indiana University Institutional Review Board.

**Patients**

The population for this study included all patients 65 years and older admitted to the medicine and medical ICU services of the 2 target hospitals during the 38-month recruitment period (November 1, 2008–December 20, 2011). During each weekday, we identified potentially eligible patients using the electronic medical record. To be eligible, patients had to be hospitalized for at least 48 hours, in order to focus on patients admitted for serious illness rather than brief stays or elective admissions for procedures. Patients were ineligible if they had been discharged or died before 48 hours of admission, had been enrolled during a previous admission, did not speak English, or were currently incarcerated, or if there was no available surrogate (Figure 1).

After each identified patient was hospitalized for at least 48 hours, the most junior physician (intern, resident, fellow, or attending) caring for the patient was paged by a research assistant and asked to complete a 3- to 5-minute screening interview regarding decision making for that patient (Figure 1). We periodically gave brief presentations of the study to physicians to encourage their assistance with enrollment. Physician interviews were conducted between 48 hours and 4 days after admission. We asked the physician to identify whether any predefined major interventions had been considered by the medical team during the first 48 hours of admission for that patient, including decisions regarding (1) life-sustaining care (eg, code status), (2) procedures and operations that required written informed consent, and (3) hospital discharge to a skilled nursing facility or similar institution. For each intervention, the physician was asked whether there was surrogate involvement in decision making (categorized as patient decision, surrogate decision, or joint patient and surrogate decisions) and the relationship of the surrogate to the patient. Physicians were paged on a daily basis until the enrollment window had passed.

We approached either the patient or the patient’s surrogate decision maker to obtain informed consent for further data collection. Patients and surrogates were approached either at bedside during hospitalization or by telephone up to 30 days after discharge. We defined the surrogate as the person, other than the patient, whom the physician identified as the primary decision maker. For enrolled patients, data regarding patient characteristics, unit location (medical ICU, progressive ICU, or hospital ward), hospital course, and outcomes were obtained from both hospitals from the electronic Regenstrief Medical Record System, which also contains death certificate information from the Indiana State Board of Health and the National Death Index. We used Medicaid insurance as a proxy for low socioeconomic status. After hospital discharge, professional research assistants reviewed clinician notes in the electronic medical record for major hospital events, the presence of advance directives, and illness severity for each patient during the first 24 hours of admission using the Cumulative Illness Rating Scale.

**Statistical Analysis**

We first determined the proportion of screened patients 65 years and older who required at least 1 major decision and the...
number for whom surrogates participated in a major decision, based on physician report. We then compared the demographic characteristics (age, race, sex, and socioeconomic status) for patients enrolled in the study with those not enrolled. For all between-group comparisons on individual measures, we used \( t \) tests or Wilcoxon nonparametric tests, depending on the distribution, for continuous variables and Fisher exact tests for categorical variables. Estimated proportions were reported with their associated binomial confidence intervals.

For all enrolled participants, we then compared patients who made their own medical decisions with those who had surrogate involvement for (1) patient characteristics, (2) hospital course and outcomes, and (3) types of decisions. Among the decisions that involved surrogates, we then examined whether patients who made their decisions jointly with the surrogates (joint group) differed from those whose surrogates made all the decisions (surrogate group). For these analyses, \( \chi^2 \) and Fisher exact tests were used for categorical variables and \( t \) tests and Wilcoxon nonparametric tests for continuous variables, as appropriate. To identify independent patient characteristics that predicted which patients needed any surrogate in their decision making, we entered all variables that differed significantly between this group and patients who made their own decisions into a multivariable logistic regression model. All statistical analyses were performed using SAS software (version 9.3; SAS Institute Inc).

Results

Patient Characteristics
We identified 10 356 hospital admissions among patients 65 years and older during the 38-month enrollment period (Figure 1). Of the 3196 who were ineligible, 27 lacked any surrogate decision maker. We conducted 1598 physician interviews (Figure 1).

According to physician reports, 1083 of 1598 hospitalized patients faced at least 1 major decision that was discussed with the patient or surrogate (67.8%; 95% CI, 65.7%-70.3%). Of these 1083 patients, 47.4% (95% CI, 44.4%-50.4%) required at least some surrogate involvement, 23.0% (20.6%-25.6%) had all decisions made by a surrogate, and 24.4% (21.9%-27.0%) had decisions made jointly by the patient and surrogate. In the ICU, surrogate decision making was even more common with surrogate involvement in 71.1% (95% CI, 63.8%-77.5%) of cases, with 43.4% (36.1%-51.0%) of patients relying solely on a surrogate and 27.7% (21.5%-35.0%) making joint decisions (Figure 2).

Among the 1083 patients identified by their provider as having faced a major medical decision, we subsequently enrolled 597 (55.1%) for further investigation. Enrolled patients were similar to those not enrolled with respect to age (mean, 76.1 vs 77.0 years; \( P = .08 \)) sex (female, 64.5% vs 60.8%; \( P = .22 \)), race (African American and other, 48.1% and 1.0% vs 52.3% and 1.3%; \( P = .33 \)), and socioeconomic status (Medicaid, 34.0% vs 31.4%; \( P = .46 \)). Among all enrolled patients, the most common reason for incapacity was Alzheimer disease
(39.4%), followed by altered mental status or encephalopathy secondary to acute medical illness (19.0%).

Patients with any surrogate involvement compared with those who made decisions on their own were older and more likely to be admitted from a nursing home, have a diagnosis of altered mental status, have Medicaid, have been admitted to an ICU, and be more seriously ill on admission (Table 1). In multivariable analyses, the odds of surrogate involvement remained significantly higher for those with an admission diagnosis of altered mental status, admission to the ICU, and older age. However, most patients (55.1%) who required a surrogate were admitted to the general medicine wards rather than the ICU (Table 1).

**Types of Surrogates and Decisions**

Among patients facing any major decision, 57.2% with a surrogate required a decision about life-sustaining care within the first 48 hours of admission, and nearly half required decisions about procedures and operations (48.6%) and discharge planning (46.9%) (Table 2). Patients with any surrogate were more likely to encounter decisions regarding life-sustaining therapy and placement. Most decisions regarding life-sustaining care involved code status and ventilators. The most common procedures were gastrointestinal endoscopy, cardiac catheterization, and central venous catheterization. Discharge planning most commonly involved placement of the hospitalized patient in a skilled nursing facility.

Surrogates were most commonly daughters (58.9%), sons (25.0%), or spouses (20.6%). Of patients with surrogate decisions, 17.7% had more than 1 primary surrogate identified by the physician. Overall, only 7.4% of patients had a living will, and 25.0% had a health care representative documented in the medical record. These documents were not significantly more common for patients with surrogates.

**Hospital Course and Outcomes**

Patients requiring any surrogate decision making experienced a more complex hospital course with greater numbers of transfers between medical teams, an increased incidence

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**Table 1. Characteristics of Patients, Based on Decision Maker**

<table>
<thead>
<tr>
<th>Variable</th>
<th>All (N = 597)</th>
<th>Patient Decision Maker (n = 354)</th>
<th>Joint (n = 141)</th>
<th>Surrogate (n = 102)</th>
<th>Surrogate + Joint (n = 243)</th>
<th>Odds of Needing Any Surrogate, Surrogate + Joint&lt;sup&gt;c&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td><strong>OR</strong> (95% CI)</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥85</td>
<td>100 (16.8)</td>
<td>35 (9.9)</td>
<td>29 (20.6)</td>
<td>36 (36.0)</td>
<td>65 (26.8)</td>
<td>6.40 (3.21-12.75)</td>
</tr>
<tr>
<td>75-84</td>
<td>215 (36.0)</td>
<td>112 (31.6)</td>
<td>63 (44.7)</td>
<td>40 (39.2)</td>
<td>103 (42.4)</td>
<td>3.26 (1.86-5.71)</td>
</tr>
<tr>
<td>70-74</td>
<td>121 (20.3)</td>
<td>84 (23.7)</td>
<td>28 (19.9)</td>
<td>9 (8.8)</td>
<td>37 (15.2)</td>
<td>1.66 (0.87-3.16)</td>
</tr>
<tr>
<td>65-69</td>
<td>161 (27.0)</td>
<td>123 (34.8)</td>
<td>21 (14.9)</td>
<td>17 (16.7)</td>
<td>38 (15.6)</td>
<td>1 [Reference]</td>
</tr>
<tr>
<td>Female sex</td>
<td>385 (64.5)</td>
<td>237 (67.0)</td>
<td>87 (61.7)</td>
<td>61 (59.8)</td>
<td>148 (60.9)</td>
<td>0.69 (0.45-1.07)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>304 (50.9)</td>
<td>181 (51.1)</td>
<td>75 (53.2)</td>
<td>48 (47.1)</td>
<td>123 (50.6)</td>
<td>1 [Reference]</td>
</tr>
<tr>
<td>Black</td>
<td>287 (48.1)</td>
<td>171 (48.3)</td>
<td>64 (45.4)</td>
<td>52 (51.0)</td>
<td>116 (47.7)</td>
<td>0.93 (0.59-1.45)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (1.0)</td>
<td>2 (0.6)</td>
<td>2 (1.4)</td>
<td>2 (2.0)</td>
<td>4 (1.7)</td>
<td>2.32 (0.20-27.36)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>203 (34.0)</td>
<td>111 (31.4)</td>
<td>43 (30.5)</td>
<td>49 (48.0)</td>
<td>92 (37.9)</td>
<td>1.57 (0.98-2.50)</td>
</tr>
<tr>
<td>Admitted from nursing home</td>
<td>66 (11.1)</td>
<td>22 (6.2)</td>
<td>17 (12.1)</td>
<td>27 (26.5)</td>
<td>44 (18.1)</td>
<td>1.61 (0.81-3.18)</td>
</tr>
<tr>
<td>Altered mental status&lt;sup&gt;d&lt;/sup&gt;</td>
<td>73 (12.3)</td>
<td>15 (4.3)</td>
<td>21 (14.9)</td>
<td>37 (36.3)</td>
<td>58 (23.9)</td>
<td>10.54 (6.51-17.06)</td>
</tr>
<tr>
<td>Site of admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Floor</td>
<td>407 (68.2)</td>
<td>273 (77.1)</td>
<td>82 (58.2)</td>
<td>52 (51.0)</td>
<td>134 (55.1)</td>
<td>1 [Reference]</td>
</tr>
<tr>
<td>Progressive ICU</td>
<td>98 (16.4)</td>
<td>51 (14.4)</td>
<td>32 (22.7)</td>
<td>15 (14.7)</td>
<td>47 (19.3)</td>
<td>1.74 (0.98-3.09)</td>
</tr>
<tr>
<td>ICU</td>
<td>92 (15.4)</td>
<td>30 (8.5)</td>
<td>27 (19.2)</td>
<td>35 (34.3)</td>
<td>62 (25.5)</td>
<td>3.36 (1.81-6.24)</td>
</tr>
<tr>
<td>Illness severity</td>
<td>22.19 (5.42)</td>
<td>21.45 (5.24)</td>
<td>22.78 (5.11)</td>
<td>23.96 (5.97)</td>
<td>23.28 (5.51)</td>
<td>1.03 (0.98-1.07)</td>
</tr>
</tbody>
</table>

Abbreviations: ICU, intensive care unit; OR, odds ratio.

<sup>a</sup> Compared with the joint group.

<sup>b</sup> Compared with the patient group.

<sup>c</sup> Adjusted for age, sex, race, Medicaid, admission status, altered mental status, site of admission, illness severity, and hospital.

<sup>d</sup> Primary admission diagnosis.

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Table 2. Decisions Discussed Within the First 48 Hours of Hospitalization, Based on Decision Maker

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. (%)</th>
<th>Patient Decision Maker (n = 354)</th>
<th>Surrogate Decision Maker (n = 243)</th>
<th>P Value*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All (N = 597)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life-sustaining therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least 1 decision in 48 h</td>
<td>294 (49.3)</td>
<td>155 (43.8)</td>
<td>139 (57.2)</td>
<td>.002</td>
</tr>
<tr>
<td>Life-sustaining therapies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code status</td>
<td>273 (45.7)</td>
<td>145 (41.0)</td>
<td>128 (52.7)</td>
<td>.01</td>
</tr>
<tr>
<td>Ventilator</td>
<td>17 (2.9)</td>
<td>5 (1.4)</td>
<td>12 (4.9)</td>
<td>.02</td>
</tr>
<tr>
<td>Artificial nutrition</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Dialysis</td>
<td>6 (1.0)</td>
<td>4 (1.1)</td>
<td>2 (0.8)</td>
<td>.71</td>
</tr>
<tr>
<td>Left ventricular assist device</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Procedures and operations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least 1 decision in 48 h</td>
<td>309 (51.8)</td>
<td>191 (54.0)</td>
<td>118 (48.6)</td>
<td>.21</td>
</tr>
<tr>
<td>Top 5 most common procedures</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Endoscopy</td>
<td>60 (10.1)</td>
<td>36 (10.2)</td>
<td>24 (9.9)</td>
<td>.91</td>
</tr>
<tr>
<td>Cardiac catheterization</td>
<td>40 (6.7)</td>
<td>35 (9.9)</td>
<td>5 (2.1)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Central venous line</td>
<td>30 (5.0)</td>
<td>7 (2.0)</td>
<td>23 (9.5)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>25 (4.2)</td>
<td>14 (4.0)</td>
<td>11 (4.5)</td>
<td>.73</td>
</tr>
<tr>
<td>Bronchoscopy</td>
<td>13 (2.2)</td>
<td>8 (2.3)</td>
<td>5 (2.1)</td>
<td>.87</td>
</tr>
<tr>
<td>Discharge planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least 1 discharge plan in 48 h</td>
<td>230 (38.5)</td>
<td>116 (32.8)</td>
<td>114 (46.9)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Discharge location discussed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing home or rehabilitation</td>
<td>179 (30.2)</td>
<td>87 (24.9)</td>
<td>92 (38.0)</td>
<td>.001</td>
</tr>
<tr>
<td>Home hospice</td>
<td>24 (4.1)</td>
<td>9 (2.6)</td>
<td>15 (6.2)</td>
<td>.03</td>
</tr>
<tr>
<td>Inpatient hospice</td>
<td>8 (1.4)</td>
<td>4 (1.1)</td>
<td>4 (1.7)</td>
<td>.60</td>
</tr>
<tr>
<td>Other</td>
<td>38 (6.3)</td>
<td>27 (7.7)</td>
<td>11 (4.6)</td>
<td>.12</td>
</tr>
</tbody>
</table>

* Compared with the patient group.

Discussion

Our observational study found that 67.8% of hospitalized older adults face at least 1 major decision in the first 48 hours of hospitalization. Surrogate decision makers were involved in these decisions for nearly half of these older adults (47.4%). Most patients who required a surrogate faced decisions about life-sustaining care, and nearly half faced decisions about procedures and operations or discharge placement. Although we found that ICU admission is associated with higher levels of surrogate decision making, most patients who required a surrogate were admitted to the general medicine service, suggesting surrogate decision making is a common phenomenon in this setting. These findings have important implications for hospital medicine and public health. In the care of hospitalized older adults, clinicians can assume that they will be in partnership and communicating with surrogate decisions makers nearly half the time when making major medical decisions.

We report a higher frequency of surrogate decision making than past studies (25%-40%),3,4 which may be due to the older age of patients in the current study and the exclusion of patients admitted for brief elective or observational stays. Our estimate of 47.4% of surrogate decision making among hospitalized elders was based on physician reports and therefore reflects that proportion of patients for whom a surrogate was in fact consulted. This may be an underestimate of the number of patients who needed a surrogate, given the finding that clinicians overestimate patients’ decision-making capacity.3,4 We found that in many cases, decisions are made jointly by surrogates and patients who are partially or temporarily incapacitated. When both parties are involved, communication and decision making involve a triad including the patient, surrogate, and clinician, which adds additional complexity to the communication process.27,28

An important implication of our findings is that novel approaches to support decision making and communication in the hospital setting must include a focus on incapacitated patients and explicitly address the role of surrogate decision makers. The current hospital structures and routines of daily bedside rounds are built on the assumption that the patient can provide historical information and make decisions independently. Perhaps because of this, there are substantial barriers to communication for surrogate decision makers.7 In the hos-

of sepsis and urinary tract infections during hospitalization, a higher use of ventilation and artificial nutrition, and longer lengths of stay (Table 3). They also differed in discharge disposition. Specifically, they were more likely to be discharged to an extended-care facility (21.2% with patient decisions and 40.9% with surrogate decisions; P < .001) and had higher hospital mortality (0.0% patients and 5.9% surrogates; P < .001) and total 30-day mortality (1.1% patients and 7.4% surrogates; P < .001).
pital, family members are considered “visitors” rather than crucial participants in their family member’s care. In-depth interviews with surrogates conducted as part of the current study found that surrogates often have trouble contacting hospital staff and struggle for information about the patient. We found that fewer than 25% of patients had a formal advance directive such as a living will or health care proxy available in the medical record. This percentage is similar to previous studies of the US population, which found that 18% to 30% of Americans have such documentation. It is likely that some completed documents were not available in the medical record during hospitalization at the time when they were most likely to be beneficial. There is clearly a continued need to improve the frequency of advance directive completion as well as systems interventions to improve their availability during decision making.

Recent work in the area of advance care planning has broadened its focus to include preparing patients and surrogates for a future time when they may need to make decisions. Our study suggests that when surrogates are needed in the hospital, they will frequently face decisions about code status, procedures, and placement, often in the setting of a critically ill or dying patient. Our findings could be used to develop novel interventions to inform potential surrogates about what they are likely to face and to prepare them for the task ahead.
at risk for the substantial burdens associated with surrogate decision making, such as posttraumatic stress and depression.6–7.

Although the impact may be somewhat lower when the patient is older, further research is needed to better quantify and address the potential effect on family members, especially outside of the ICU in the general medicine setting.

Our study has several limitations. It was conducted in 2 hospitals in 1 metropolitan area and may not be generalizable to other settings. We recruited patients from medicine services, which may differ from surgery or other services. The involvement of surrogates was determined by physician interview, which reflects the extent to which physicians rely on surrogates but is not based on a formal assessment of decisional capacity. We were unable to contact physicians for 1770 potentially eligible patients (most commonly because physicians did not return pages), and it is possible that patients for whom we completed interviews differed from those for whom we did not. Physician interviews were conducted after 48 hours of hospitalization and therefore reflect a “snapshot” of decision making early in the hospital stay. We excluded patients with brief overnight stays, which may have inflated the proportion with major decisions. Conversely, some patients may have had long, complex hospitalizations with major decisions that arose later in the hospital stay after our screening period. Finally, some decisions that we are counting as “major” may have seemed routine or straightforward to the clinicians or surrogates. A strength of our study is our method of patient identification and physician screening, which allowed us to prospectively collect real-time information about the process of decision making and the role of surrogates.

Conclusions

Surrogate decision making is a common occurrence for hospitalized older adults, and more than half of surrogates face decisions about code status or other life-prolonging therapies. Although a variety of family members play a role, decisions are most commonly made by daughters without the help of living wills or previously appointed health care power of attorney forms. Furthermore, surrogate decision making involves patients who require high-intensity care, have more resource utilization, and are at a greater risk of death. They are therefore an important group on which to focus efforts at appropriate advance care planning and high-quality decision making at the time of serious illness, including choosing appropriate medical interventions and fostering excellent communication with surrogate decision makers.

ARTICLE INFORMATION

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Author Contributions: Dr Torke had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Torke, Sachs, Helft, Montz, Hui, Callahan.

Acquisition of data: Torke, Montz.

Analysis and interpretation of data: All authors.

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REFERENCES


Mrs H, an 85-year-old woman with atrial fibrillation, congestive heart failure, and hemiplegia from a previous stroke, died in the intensive care unit (ICU) after a decision to withdraw mechanical ventilation. In recounting this decision, her daughter, MP, reported that it was the last in a series of difficult treatment choices that began months earlier. She participated in decisions to admit her mother to a nursing home because of recurrent falls, transfer her to the community hospital because of mental status changes, move her from the community hospital to a referral hospital when a stroke was diagnosed, and place a feeding tube when she failed a swallowing test. By the time she was admitted to the ICU with pneumonia, Mrs H had been through so much that “she was not my mother anymore,” MP said. Poignantly, MP explained that the decision to withdraw life-sustaining treatment was easier than the earlier decision—made on the hospital ward—to permit the feeding tube. She knew her mother would never have wanted the feeding tube but said that she had felt pressured by the neurologist’s recommendation to “give her a chance.”

Research on surrogate decision making has focused on decisions in the ICU. Studies have documented surrogate distress and adverse mental health outcomes associated with participation in ICU decisions about life-sustaining treatment,1,2 and interventions to support surrogate decision making have focused on improving the quality of communication with families in the ICU.3 For example, frequent and structured family meetings improve patient and family outcomes and are now recommended by professional society guidelines.

Yet, as Mrs H’s story illustrates, family involvement in treatment decisions for older adults often evolves over months or even years before a patient’s admission to the ICU. A decision to withdraw life-sustaining treatment may represent the last of many difficult choices that include surrogates to varying degrees. Earlier decisions may affect the overall course of an illness, the issues faced at the end of life, and the level of surrogate distress. Until now, the prevalence and significance of...