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Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults

Alexia M. Torke, MD, MS^{1,2,3,4}, Greg A. Sachs, MD^{1,2,3}, Paul R. Helft, MS^{4,5}, Kianna Montz, MA^{1,2}, Siu L. Hui, PhD^{1,2,6}, James E. Slaven, MS⁶, and Christopher M. Callahan, MD^{1,2,3}

¹Indiana University (IU) Center for Aging Research, Indianapolis, Indiana

²Regenstrief Institute, Inc., Indianapolis, Indiana

³IU Division of General Internal Medicine and Geriatrics, Indianapolis, Indiana

⁴Fairbanks Center for Medical Ethics, IU Health, Indianapolis, Indiana

⁵IU Melvin and Bren Simon Cancer Center, Indianapolis, Indiana

⁶IU Department of Biostatistics, Indianapolis, Indiana

Abstract

Importance—Hospitalized older adults often lack decisional capacity, but outside of the intensive care unit (ICU) 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—Prospective, observational study.

Setting—Medical and Medical ICU services of two hospitals in one Midwest city.

Participants—1083 hospitalized older adults identified by their physicians as requiring major medical decisions.

Measures—Clinical characteristics, hospital outcomes, nature of major medical decisions and surrogate involvement.

Results—Based on physician reports at 48 hours of hospitalization, 47.4% (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 one decision within 48 hours, 57.2% required decisions about life sustaining care (mostly addressing code status), 48.6% about procedures and surgeries and 46.9% about discharge planning. Patients who required a surrogate experienced a more complex hospital course with greater use of ventilators (2.5% patients who made decisions, 13.2% patients who required any surrogate decisions, $p < 0.0001$), artificial nutrition (1.7% patient, 14.4% surrogate, $p < 0.0001$) and greater length of stay (median 6 days patient, 7 days surrogate, $p < 0.0001$). They were more likely to be discharged to an extended care facility (21.2% patient, 40.9% surrogate, $p < 0.0001$), and had higher hospital mortality (0.0% patient; 5.9% surrogate, $p < 0.0001$). Most surrogates were daughters (58.9%), sons (25.0%) or spouses (20.6%). Overall, only 7.4% had a living will and 25.0% a health care representative document in the medical record.

Conclusion—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 both the ICU and the hospital ward setting. Hospital functions should be redesigned to account for the large and growing role of surrogates and to support surrogates as they make health care decisions.

As the population ages, a greater number of hospitalized older adults will present with impaired cognition due to a rising prevalence of Alzheimer’s disease,¹ delirium² 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%³ and 40%⁴ lacked the capacity to make medical decisions based on standardized assessment, and studies of hospitalized older adults report that 43% suffer from some degree of cognitive impairment.⁵

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 previously 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.^{6,7} There is some evidence that key decisions such as writing Do Not Resuscitate orders may even be delayed when surrogates are required to make these decisions.⁸ Prior studies of decision making capacity in the hospital have not examined how often surrogates are called upon to make decisions or described the decisions encountered by surrogates.³⁻⁵

Research on the topic of surrogate decision making has instead focused on surrogates’ accuracy in hypothetical situations regarding future decision making,⁹ identified the burdens and distress experienced by surrogates,¹⁰⁻¹⁷ and described surrogate perspectives on various aspects of decision making.¹⁸⁻²¹ However, the majority of this work has focused on decision making in the ICU,^{17,18,20-22} the nursing home^{10,11} or in the setting of end of life care.^{12,14,22}

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 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 two hospitals in one Midwestern city. The first was a university-affiliated, 316-bed urban, public hospital with over 15,000 admissions/year. The second was a 1462-bed university-affiliated tertiary care referral center that has over 58,000 admissions/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 and older admitted to the medicine and medical ICU services of the two target hospitals during the 38 month recruitment period (November 2008–December 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 prior to 48 hours of admission, had been enrolled during a prior admission did not speak English, 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 3–5 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: 1) decisions regarding life sustaining care (e.g. code status, intubation, artificial nutrition); 2) decisions regarding procedures and surgeries that required written informed consent; and 3) decisions about 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/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 were approached either at bedside during hospitalization or by phone up to 30 days after discharge. Surrogates were contacted at bedside or by phone during hospitalization or 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 (RMRS).^{23,24} The RMRS 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 socio-economic 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.^{25,26}

Data analysis

We first determined the proportion of screened patients aged 65 and older who required at least one 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, gender, SES) for patients enrolled in the study with those not enrolled. For all between-group comparisons on individual measures, we used Student's t-tests or Wilcoxon non-parametric tests, depending on the distribution, for continuous variables and Fisher's Exact tests for categorical variables. Estimated proportions were reported with their associated binomial confidence intervals.

For all enrolled subjects, we then compared patients who made their own medical decisions with those patients who had any 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 patients whose surrogates made all the decisions

(surrogate group). For these analyses, Chi-Square/Fisher's Exact tests were used for categorical variables and Student's t-tests/Wilcoxon 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. These odds ratios of needing any surrogates were estimated with their associated confidence intervals. All statistical analyses were performed using SAS software (SAS v9.3, SAS Institute, Cary, NC).

RESULTS

Patient Characteristics

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

Based on physician reports, 1083 of 1598 hospitalized patients faced at least one major decision that was discussed with the patient or surrogate (67.8%; 95% Confidence Interval 65.7–70.3). Of these 1083 patients, we found that 47.4% (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% (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. Patients who were enrolled were similar to those not enrolled with respect to age (mean 76.1 v. 77.0, $p=0.079$), sex (64% female v. 60.8%, $p=0.223$), race (48.1% African American and 1.0% other v. 52.3% African American and 1.3% other, $p=0.331$) and SES (Medicaid 34.0% v. 31.4% $p=0.463$). Among all enrolled patients, the most common reason for incapacity was Alzheimer's disease (39.4%), followed by altered mental status/encephalopathy secondary to acute medical illness (19.0%).

Patients with any surrogate involvement compared to those who made decisions on their own were older, 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 were 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 greater age. However, the majority of 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% of patients 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 surgeries (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 one 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, higher incidence of sepsis and urinary tract infections during hospitalization, 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% patient, 40.9% surrogate, $p < 0.0001$) and had higher hospital mortality (0.0% patient; 5.9% surrogate, $p < 0.0001$) and total 30-day mortality (1.1% patient, 7.4% surrogate, $p < 0.0001$).

DISCUSSION

Our observational study found that 68% of hospitalized older adults face at least one 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%). The majority of patients who required a surrogate faced decisions about life sustaining care, and nearly half faced decisions about procedures and surgeries or discharge placement. Although we found that ICU admission is associated with higher levels of surrogate decision making, the majority of 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%), which may be due to the older age of patients in the current study and exclusion of patients admitted for brief elective or observational stays. Our estimate of 47% 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 involves 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 upon the assumption that the patient can both provide historical information and make decisions independently. Perhaps because of this, there are substantial barriers to communication for surrogate decision makers.⁷ In the hospital, 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.¹⁹ Clinicians also frequently report making decisions with surrogates to be highly stressful.²⁹ Prior studies point to strategies to improve family outcomes such as early family meetings in the ICU,³⁰ or giving families increased time to

speak during the meetings.³¹ Such communication strategies should be built into the hospital structure as a central element of good patient care and should not be limited to the ICU.

We found that patients who require a surrogate are sicker, have more in-hospital transfers of care, and are more likely to die. This is consistent with prior findings of worse hospital outcomes for patients with cognitive impairment.^{5,32,33} Given the high resource use and complexity of care, such patients should be a focus of efforts to provide high quality and effective medical care and to avoid care that is unnecessary or harmful. Geriatrics consultation may be able to aid in cases where decision making impairment is reversible, and palliative care consultation may improve communication for this group of patients.

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 chart. This percentage is similar to prior studies of the US population, which found that 18–30% of Americans have such documentation.³⁴ 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.³⁵ There is clearly a continued need to improve the frequency of advance directive completion as well as systems interventions to improve their availability at time of decision making.³⁶

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.³⁷ 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.

Finally, given the fact that over 13 million older adults are admitted to the hospital annually, many family members are at risk for the substantial burdens associated with surrogate decision making, such as post-traumatic stress, depression and PTSD.^{15,17} Although the impact may be somewhat lower when the patient is older,³⁸ further research is needed to better quantify and address the potential impact on family members, especially outside of the ICU in the general medicine setting.

Our study has several limitations. It was conducted in two hospitals in one metropolitan area and may not generalize 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, it 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 very 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 was 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.

In conclusion, surrogate decision making is a very common occurrence for hospitalized older adults, and over half of surrogates face decisions about code status and 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 high resource utilization and are at high 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.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Alzheimer's Association. Alzheimer's Disease Facts and Figures. Washington, D.C: Alzheimer's Association; 2011.
2. Inouye SK, Schlesinger MJ, Lydon TJ. Delirium: a symptom of how hospital care is failing older persons and a window to improve quality of hospital care. *American Journal of Medicine*. May; 1999 106(5):565–573. [PubMed: 10335730]
3. Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? *JAMA*. Jul 27; 2011 306(4):420–427. [PubMed: 21791691]
4. Raymont V, Bingley W, Buchanan A, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet*. Oct 16–22; 2004 364(9443):1421–1427. [PubMed: 15488217]
5. Boustani M, Baker MS, NC, et al. Impact and recognition of cognitive impairment among hospitalized elders. *J Hospital Med*. 2010; 5(2):69–75.
6. Buchanan, Brock. *Deciding for others: The ethics of surrogate decision making*. Cambridge: Cambridge University Press; 1990.
7. Dubler NN. The doctor-proxy relationship: the neglected connection. *Kennedy Inst Ethics J*. Dec; 1995 5(4):289–306. [PubMed: 10153758]
8. Torke AM, Sachs GA, Helft PR, et al. Timing of do-not-resuscitate orders for hospitalized older adults who require a surrogate decision-maker. *J Am Geriatr Soc*. Jul; 2011 59(7):1326–1331. [PubMed: 21732923]
9. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med*. Mar 13; 2006 166(5):493–497. [PubMed: 16534034]
10. Butcher HK, Holkup PA, Park M, Maas M. Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Res Nurs Health*. Dec; 2001 24(6):470–480. [PubMed: 11746076]

11. Park M, Butcher HK, Maas ML. A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Res Nurs Health*. Oct; 2004 27(5):345–356. [PubMed: 15362145]
12. Chambers-Evans J, Carnevale FA. Dawning of awareness: the experience of surrogate decision making at the end of life. *Journal of Clinical Ethics*. 2005; 16(1):28–45. [PubMed: 15915844]
13. Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med*. Sep; 2007 22(9):1274–1279. [PubMed: 17619223]
14. Braun UK, Beyth RJ, Ford ME, McCullough LB. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *J Gen Intern Med*. Mar; 2008 23(3):267–274. [PubMed: 18172738]
15. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med*. May 1; 2005 171(9):987–994. [PubMed: 15665319]
16. Wendler D, Rid A. Systematic Review: The effects on surrogates of making treatment decisions for others. *Ann Intern Med*. 2011; 154:336–346. [PubMed: 21357911]
17. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. *Crit Care Med*. 2012; 40:618–624. [PubMed: 22080636]
18. Majesko A, Hong SY, Weissfeld L, White DB. Identifying family members who may struggle in the role of surrogate decision maker. *Crit Care Med*. Aug; 2012 40(8):2281–2286. [PubMed: 22809903]
19. Torke AM, Petronio S, Purnell C, Sachs GA, Helft PR, Callahan CM. Communicating with Clinicians: A Study of Surrogates for Hospitalized Older Adults. *J Amer Geriatr Soc*. 2012; 60:1401–1407. [PubMed: 22881864]
20. Schenker Y, White DB, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM. “It hurts to know... and it helps”: exploring how surrogates in the ICU cope with prognostic information. *J Palliat Med* Mar. 2013; 16(3):243–249.
21. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. *J Gen Intern Med*. Dec; 2012 27(12):1657–1665. [PubMed: 23011253]
22. Azoulay E, Pochard F, Chevret S, et al. Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: a multicenter, prospective, randomized, controlled trial. *Am J Respir Crit Care Med*. Feb 15; 2002 165(4):438–442. [PubMed: 11850333]
23. McDonald CJ, Blevins L, Tierney WM, Martin DK. The Regenstrief medical records. *MD Computing*. Sep-Oct; 1988 5(5):34–47. [PubMed: 3231034]
24. McDonald CJ, Overhage JM, Tierney WM, et al. The Regenstrief Medical Record System: a quarter century experience. *International Journal of Medical Informatics*. Jun; 1999 54(3):225–253. [PubMed: 10405881]
25. Linn BS, Linn MW, Gurel L. Cumulative Illness Rating Scale. *J Amer Geriatr Soc*. 1968; 16:622–626. [PubMed: 5646906]
26. Salvi F, Miller MD, Grilli A, et al. A Manual of Guidelines to Score the Modified Cumulative Illness Rating Scale and Its Validation in Acute Hospitalized Elderly Patients. *J Amer Geriatr Soc*. 2008; 56:1926–1931. [PubMed: 18811613]
27. Petronio S, Sargent J, Andrea L, Reganis P, Cichocki D. Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. *Journal of Social and Personal Relationships*. 2004; 21:33–52.
28. Karnieli-Miller O, Werner P, Neufeld-Kroszynski G, Eidelman S. Are you talking to me?! An exploration of the triadic physician-patient-companion communication within memory clinics encounters. *Patient Educ Couns*. Sep; 2012 88(3):381–390. [PubMed: 22789148]
29. Torke AM, Siegler M, Abalos A, Moloney RM, Alexander GC. Physicians' experiences with surrogate decision making for hospitalized adults. *J Gen Intern Med*. 2009; 24:1023–1028. [PubMed: 19633896]

30. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU.[see comment]. *New England Journal of Medicine*. Feb 1; 2007 356(5):469–478. [PubMed: 17267907]
31. McDonagh JR, Elliott TB, Engelberg RA, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine*. Jul; 2004 32(7):1484–1488. [PubMed: 15241092]
32. Witlox J, Eurelings LS, de Jonghe JF, Kalisvaart KJ, Eikelenboom P, van Gool WA. Delirium in elderly patients and the risk of postdischarge mortality, institutionalization, and dementia: a meta-analysis. *JAMA*. Jul 28; 2010 304(4):443–451. [PubMed: 20664045]
33. Khan BA, Zawahiri M, Campbell NL, et al. Delirium in hospitalized patients: implications of current evidence on clinical practice and future avenues for research--a systematic evidence review. *J Hosp Med*. Sep; 2012 7(7):580–589. [PubMed: 22684893]
34. Wilkinson, A.; Wenger, N.; Shugarman, LR. *Literature Review on Advance Directives*. Washington, DC: 2007.
35. Fagerlin A, Schneider CE. Enough: The Failure of the Living Will. *Hastings Cent Rep*. 2004; 34(2):30–42. [PubMed: 15156835]
36. Hickman SE, Hammes BJ, Moss AH, Tolle SW. Hope for the future: achieving the original intent of advance directives. *Hastings Cent Rep*. Nov-Dec;2005 (Spec No):S26–30. [PubMed: 16468252]
37. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*. Aug 17; 2010 153(4):256–261. [PubMed: 20713793]
38. Kross EK, Engelberg RA, Gries CJ, Nielsen EL, Zatzick D, Curtis JR. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. *Chest*. 2011; 139:795–801. [PubMed: 20829335]

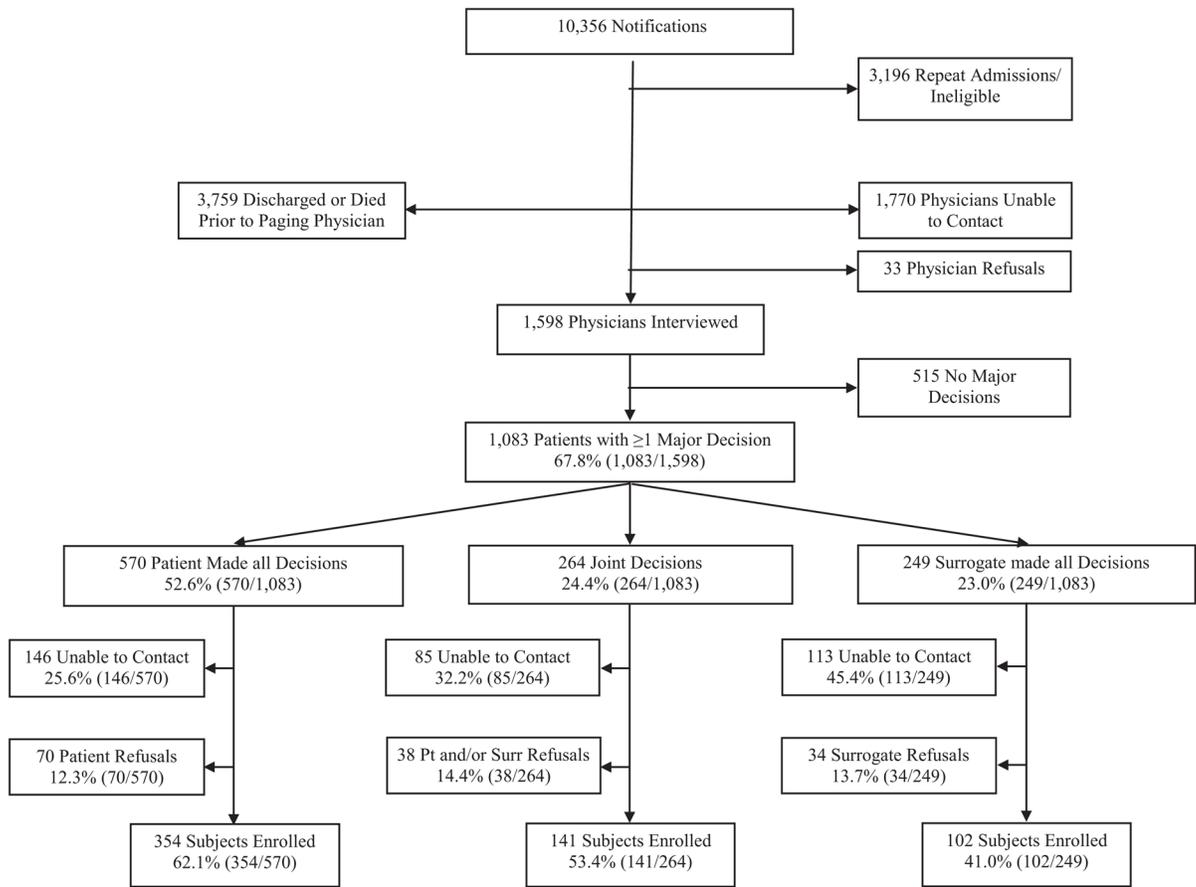


Figure 1.
Enrollment of Study Participants

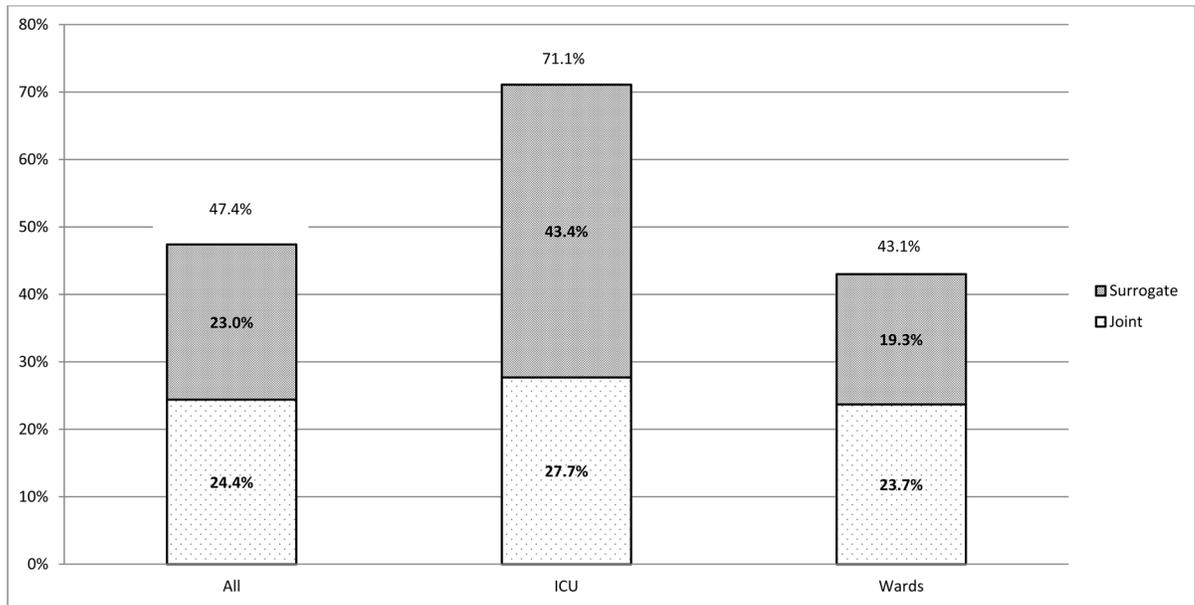


Figure 2.
Percentage of Patients Requiring Surrogate Decision Making, by Admission Location

Table 1

Characteristics of Patients, Based on Decision Maker

Variable	All n=597	Patient Decision Maker n=354	Any Surrogate Involvement in Decision Making					Odds of needing any surrogate (Surrogate+Joint) ^c
			Joint n=141	Surrogate n=102	Surrogate +Joint n=243			
	N (%)	N (%)	N (%)	N (%)	p ^a	N (%)	p ^b	OR ^b (95% CI)
Age					0.0180		< 0.0001	
85+ vs.	100 (16.8)	35 (9.9)	29 (20.6)	36 (36.0)		65 (26.8)		6.40 (3.21–12.75)
75–84	215 (36.0)	112 (31.6)	63 (44.7)	40 (39.2)		103 (42.4)		3.26 (1.86–5.71)
70–74	121 (20.3)	84 (23.7)	28 (19.9)	9 (8.8)		37 (15.2)		1.66 (0.87–3.16)
64–69	161 (27.0)	123 (34.8)	21 (14.9)	17 (16.7)		38 (15.6)		Ref
Gender (Female)	385 (64.5)	237 (67.0)	87 (61.7)	61 (59.8)	0.7647	148 (60.9)	0.1295	0.69 (0.45–1.07)
Race					0.6272		0.4289	
White	304 (50.9)	181 (51.1)	75 (53.2)	48 (47.1)		123 (50.6)		Ref
Black	287 (48.1)	171 (48.3)	64 (45.4)	52 (51.0)		116 (47.7)		0.93 (0.59–1.45)
Other	6 (1.0)	2 (0.6)	2 (1.4)	2 (2.0)		4 (1.7)		2.32 (0.20–27.36)
Medicaid	203 (34.0)	111 (31.4)	43 (30.5)	49 (48.0)	0.0054	92 (37.9)	0.0993	1.57 (0.98–2.50)
Admitted from Nursing Home	66 (11.1)	22 (6.2)	17 (12.1)	27 (26.5)	0.0040	44 (18.1)	< 0.0001	1.61 (0.81–3.18)
Altered Mental Status ^d	73 (12.3)	15 (4.3)	21 (14.9)	37 (36.3)	0.0001	58 (23.9)	< 0.0001	10.54 (6.51–17.06)
Site of Admission					0.0198		< 0.0001	
Floor	407 (68.2)	273 (77.1)	82 (58.2)	52 (51.0)		134 (55.1)		Ref
Progressive ICU	98 (16.4)	51 (14.4)	32 (22.7)	15 (14.7)		47 (19.3)		1.74 (0.98–3.09)
ICU	92 (15.4)	30 (8.5)	27 (19.2)	35 (34.3)		62 (25.5)		3.36 (1.81–6.24)
Illness Severity	22.19 (5.42)	21.45 (5.24)	22.78 (5.11)	23.96 (5.97)	0.0996	23.28 (5.51)	< 0.0001	1.03 (0.98–1.07)

^a compared to joint group

^b compared to patient group

^c Adjusted for age, gender, race, Medicaid, admission status, altered mental status, site of admission, illness severity and hospital

^d Primary admission diagnosis

Table 2

Decisions Discussed within the First 48 Hours of Hospitalization, Based on Decision Maker

Variable	All n=597	Patient Decision Maker n=354	Surrogate Decision Maker n=243	
	N (%)	N (%)	N (%)	<i>p</i> ^a
Life sustaining therapy				
At least one decision in 48 h	294 (49.3)	155(43.8)	139 (57.2)	0.0015
Life sustaining therapies decisions				
Code status	273 (45.7)	145 (41.0)	128 (52.7)	0.0058
Ventilator	17 (2.9)	5 (1.4)	12 (4.9)	0.0212
Artificial nutrition	0 (0)	0 (0)	0 (0)	n/a
Dialysis	6 (1.0)	4 (1.1)	2 (0.8)	0.7121
Left ventricular assist device	0 (0)	0 (0)	0 (0)	n/a
Procedures/surgeries				
At least one decision in 48 h	309 (51.8)	191 (54.0)	118 (48.6)	0.2114
Top 5 most common procedures				
Endoscopy	60 (10.1)	36 (10.2)	24 (9.9)	0.9069
Cardiac catheterization	40 (6.7)	35 (9.9)	5 (2.1)	0.0002
Central venous line	30 (5.0)	7 (2.0)	23 (9.5)	<0.0001
Blood transfusion	25 (4.2)	14 (4.0)	11 (4.5)	0.7318
Bronchoscopy	13 (2.2)	8 (2.3)	5 (2.1)	0.8679
Discharge Planning				
At least one discharge plan in 48 h	230 (38.5)	116 (32.8)	114 (46.9)	<0.0001
Discharge location discussed				
Nursing home/rehab	179 (30.2)	87 (24.9)	92 (38.0)	0.0006
Home hospice	24 (4.1)	9 (2.6)	15 (6.2)	0.0278
Inpatient hospice	8 (1.4)	4 (1.1)	4 (1.7)	0.5972

Variable	All n=597	Patient Decision Maker n=354	Surrogate Decision Maker n=243	
	N (%)	N (%)	N (%)	P ^a
Other	38 (26.3)	27 (7.7)	11 (4.6)	0.1220

^a compared to patient group

Table 3

Hospital Course and Outcomes, Based on Decision Maker

Variable	All n=597	Patient Decision Maker, n=354	Surrogate Decision Maker n=243	P ^a
	N (%)	N (%)	N (%)	
Number of Team Changes		323 (91.2)	200 (82.3)	0.0009
0	523 (87.6)			
1	57 (9.6)	21 (5.9)	36 (14.8)	
2	15 (2.5)	10 (2.8)	5 (2.1)	
3 or more	2 (0.3)	0 (0)	2 (0.8)	
DNR order during admission	66 (11.1)	32 (9.0)	34 (14.0)	0.0580
Clinical events during admission				
Pulmonary Embolus	1 (0.2)	1 (0.3)	0	0.4070
Myocardial Infarct	29 (4.9)	17 (4.8)	12 (4.9)	0.9395
Fall	5 (0.8)	2 (0.6)	3 (1.2)	0.3778
Urinary Tract Infection	114 (19.1)	50 (14.1)	64 (26.3)	0.0002
Sepsis	58 (9.7)	25 (7.1)	33 (13.6)	0.0082
Stroke	8 (1.3)	4 (1.1)	4 (1.7)	0.5900
Interventions during admission				
Artificial Ventilation	41 (6.9)	9 (2.5)	32 (13.2)	<0.0001
Cardiac Arrest/Resuscitation	3 (0.5)	3 (0.9)	0	0.2747
Artificial Nutrition	41 (6.9)	6 (1.7)	35 (14.4)	<0.0001
Dialysis	39 (6.5)	24 (6.8)	15 (6.20)	0.8667
Length of Stay (Median, range)	6 (1 – 40)	6 (2 – 27)	7 (1 – 40)	<0.0001
Discharge Location				
Home	258 (43.3)	201 (56.8)	57 (23.6)	<0.0001
Home with Home Health Care	99 (16.6)	59 (16.7)	40 (16.5)	
Extended Care Facility	174 (29.2)	75 (21.2)	99 (40.9)	
	16 (2.7)	5 (1.4)	11 (4.5)	

Variable	All n=597	Patient Decision Maker, n=354	Surrogate Decision Maker n=243	p ^a
Hospice	N (%) 13 (2.2)	N (%) 7 (2.0)	N (%) 6 (2.5)	
Other Hospital	N (%) 23 (3.9)	N (%) 7 (2.0)	N (%) 16 (6.6)	
Long Term Acute Care Hospital	N (%) 14 (2.3)	N (%) 0 (0)	N (%) 14 (5.8)	
In-Hospital Mortality				
In Hospital Mortality	14(2.5)	0 (0)	14 (5.9)	< 0.0001
Total 30 Day Mortality	22 (3.7)	4 (1.1)	18 (7.4)	< 0.0001

^a compared to patient group