ORIGINAL RESEARCH

Medical Decision-making During the Guardianship Process for Incapacitated, Hospitalized Adults: A Descriptive Cohort Study

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BACKGROUND: It is sometimes necessary for courts to appoint guardians for adult, incapacitated patients. There are few data describing how medical decisions are made for such patients before and during the guardianship process.

OBJECTIVE: To describe the process of medical decision-making for incapacitated, hospitalized adults for whom court-appointed guardians are requested.

DESIGN: Retrospective, descriptive cohort study.

MEASUREMENTS: Patients were identified from the legal files of a public, urban hospital. Medical and legal records were reviewed for demographic data, code status, diagnoses, code status orders and invasive procedures and person authorizing the order or procedure, dates of incapacitation and appointment of temporary guardian, reason for guardianship, and documentation of communication with a guardian.

RESULTS: A total of 79 patients met inclusion criteria; 68.4% were male and 56.2% African-American. The median age was 65 years. Of the 71 patients with medical records available 89% of patients had a temporary guardianship petitioned because of the need for placement only. Seventeen patients had a new DNR order written during hospitalization, eight of which were ordered by physicians without consultation with a surrogate decision maker. Overall, 32 patients underwent a total of 81 documented invasive procedures, 16 of which were authorized by the patient, 15 by family or friend, and 11 by a guardian; consent was not required for 39 of the procedures because of emergency conditions or because a procedure was medically necessary and no surrogate decision maker was available.

CONCLUSIONS: Although most of the guardianships were requested for placement purposes, important medical decisions were made while patients were awaiting appointment of a guardian. Hospitalized, incapacitated adults awaiting guardianship may lack a surrogate decision maker when serious decisions must be made about their medical care.

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INTRODUCTION

When hospitalized adults are unable to make their own medical decisions, clinicians usually turn to patients' close family members and friends. Little has been written about what happens in situations where incapacitated patients require medical care and are "unbefriended," meaning that they have no legally authorized surrogate, family member, or friend willing or able to speak on their behalf.[1,2] Depending on state law, it is sometimes necessary for the courts to appoint a guardian for incapacitated patients who have no surrogate decision makers available. One problem with this system is that court-appointed guardians are often unfamiliar with the patient and have little contact with the medical professionals treating the patients.[3] Another problem is that the time required for the appointment of a guardian may deprive the incapacitated patient of a surrogate decision maker during a portion of their hospitalization.

Although a few studies have been conducted regarding the relationship between family members who act as surrogate decision-makers and physicians and other medical personnel,[4–8] we currently lack data about the characteristics of decisions and the process of decision-making for patients without family decision-makers.[2,9] We are unaware of any studies describing the effect of guardianship appointment or the guardianship process on medical decisions for incapacitated, unbefriended patients.

In order to examine these issues, we conducted a retrospective review of legal and medical records for incapacitated, adult patients for whom a guardian was appointed during an acute care hospitalization. The objectives of the study were to 1) describe the socio-demographic and medical characteristics of these patients; 2) describe the identity of persons authorizing medical decisions during the target hospitalization; and 3) examine how health care professionals and court-appointed guardians communicate. This study is a descriptive cohort study intended to identify issues regarding medical decision-making while patients await appointment of a guardian. It is

not intended to be a review of guardianship reform or to provide detailed recommendations. The study was approved by the Institutional Review Board of Indiana University-Purdue University at Indianapolis.

METHODS

Patient Population

We included adult patients admitted to Wishard Memorial Hospital (WMH), a large, tax-supported public hospital which serves patients in Indianapolis, Indiana and the surrounding areas in Marion County. Using the hospital's legal files, we identified all adult patients 18 years of age or older admitted to WMH between January 1, 2004 and December 31, 2007 for whom a petition for temporary (emergency) guardianship was filed by the hospital's legal counsel during the hospitalization. Requests for petitions for guardianship in this institution are initiated by a medical team member after it has been determined that the patient does not have decision-making capacity and has no surrogate decision maker willing or available to act on behalf of the patient.

Indiana Guardianship Process

In Indiana, processes governing surrogate decision-making and the court appointment of guardians are spelled out in Indiana's Health Care Consent Act. This statute provides that, in the absence of a statutorily approved family member or appointed health care representative, consent to health care may be given by a judicially appointed guardian.[10] The court appoints a temporary guardian on an emergency basis to make health care decisions for a maximum period of 60 days or until a court hearing can be held to appoint a permanent guardian.[11] If no family member or friend is found that is willing to act as a permanent guardian within the 60 day time period, the court appoints a state-provided guardian (usually the same guardian appointed as the temporary guardian) as a permanent guardian. During the study period guardians in Marion County were provided by the Marion County Office of Family and Children and the Family and Social Services Division of Family Resources. As of March of 2008 guardians are provided by a private contractor.[12] Although the guardianship provider has changed, the process for obtaining a guardian has remained the same.

Data Collection

Patients' paper medical charts were reviewed by one of the investigators (RJB). Paper records included both hand written chart notes and printouts of electronic notes by physicians and other clinicians, as well as copies of all orders entered into the Computerized Physician Order Entry System, consent forms, and billing and coding information. We used the paper chart to collect demographic information, documentation of invasive procedures, and admission diagnosis. Diagnoses that caused incapacitation were also collected. Information about code status orders (full code, partial code, or do not resuscitate) was found by reviewing copies of electronic physician orders.

The number of invasive procedures potentially requiring informed consent was collected from the billing list in each patient's medical chart and matched to an informed consent document or chart note documenting consent. Procedures were then sorted into categories of ventilator, surgery, percutaneous endoscopic gastrostomy (PEG) tube, diagnostic tests, catheterization, transfusion, or dialysis. Consent by patient, family or friend, or court-appointed guardian was determined from chart notes or informed consent documents indicating consent. Procedures were captured as 'consent not required' if they were performed due to an emergency (e.g. mechanical ventilation due to respiratory distress) or if a chart note indicated that the patient's condition would worsen without treatment and an appropriate surrogate could not be contacted. In Indiana consent is not required for emergency care of a patient or when a patient is incompetent, requires medical or surgical treatment that is medically necessary, and there is concurrence of a second opinion.[13]

The date of incapacitation and the dates that guardianship was requested and appointed were collected to determine length of time between incapacitation and guardianship appointment. The date of incapacitation was defined as the first instance of documented incapacitation (e.g. documentation of delirium, unresponsiveness, sedation, statements that the patient was unable to participate in decisions, or signature of someone other than patient on a written informed consent document.) The 'guardianship request date' was defined as the date guardianship was requested through the court. The authority of the temporary guardian was effective on this date. The 'date of appointment' was defined as the date that a permanent guardian was appointed.

We collected information from the legal and medical records regarding the documented reason for the guardianship request. Chart notes were reviewed for documentation regarding communication between medical professionals and the court-appointed guardian. Specifically, we extracted evidence of discussion about 1) change from aggressive to palliative care; 2) placement; 3) interventions requiring informed consent; and 4) removing life support.

Data Analysis

Descriptive statistics were used to summarize patient characteristics and other variables, including frequency and percent for categorical variables and mean, standard deviation, minimum, maximum, and median for continuous variables. The *N* presented in each table only includes patients with non-missing values for the relevant variable.

RESULTS

Patient Characteristics

Seventy-nine patients met the inclusion criteria based on data retrieved from legal files. Of these 79 patients, eight did not have a medical record available, four due to a lack of

identifiable information in the legal file (e.g. medical record number) and four due to unavailability of records during the data collection period. Sixty-eight percent were male and over half were African-American (Table 1). Half of the patients had Medicare as their primary payer (Table 1). Fourteen (19.7%) patients were admitted primarily for a psychiatric disorder, including schizophrenia, mental retardation, depressive disorder, etc., and 2.8% had an admission diagnosis of dementia (Table 2). The most common cause of incapacity was dementia (45.1%; Table 3). Fifty-two (73.2%) of 71 patients were living alone or with friends or family at admission and 60 (84.5%) of 71 patients were placed in an extended care facility at discharge (Table 4).

Hospital Course

Code Status. Sixty-nine (97.2%) of 71 patients were considered to have full code status at admission (Table 5). Thirty-six (50.7%) of these patients had an admission note documenting full code status and, consistent with hospital policy, the 33 (46.5%) patients without code status documentation were assumed to have full code status. One patient had a do not resuscitate (DNR) order and one patient had a partial code order at admission. A partial code, which is an option at the institution where the study was conducted, indicates that a patient has elected to receive only some components of cardiopulmonary resuscitation (e.g., medications but no intubation).[14] Seventeen (24.3%) of the 70 patients with partial or full code status at admission had DNR orders written during the target hospitalization (Table 5). Eight of the 17 DNR orders were written by physicians, based on medical criteria and the worsening condition of the patient, while awaiting appointment of a temporary guardian or while the guardian was obtaining court approval for the DNR order.

Table 1. Summary of Demographic and Payer Characteristics

Gender (*N*=79)	*n* (%)	
M	54 (68.4%)	
F	25 (31.6%)	
Age in years (*N*=77)		
Mean (SD)	65 (15)	
Minimum	27	
Median	65	
Maximum	100	
Race (*N*=73)	*n* (%)	
African American	41 (56.2%)	
White	30 (41.1%)	
Hispanic	2 (2.7%)	
Payer	Primary (*N*=70)	Secondary (*N*=70)
	n (%)	*n* (%)
Medicare	35 (50.0%)	2 (2.9%)
Medicaid pending	12 (17.1%)	9 (12.9%)
Medicaid	6 (8.6%)	16 (22.9%)
Medicare psych	6 (8.6%)	0 (0.0%)
Self pay	5 (7.1%)	1 (1.4%)
Wishard advantage[a]	2 (2.9%)	6 (8.6%)
No secondary payer	0 (0.0%)	33 (47.1%)
Other[b]	4 (5.7%)	3 (4.3%)

[a]*Managed care program operated by the hospital*
[b]*Other: Commercial, Veteran's Administration, or Worker's Compensation*
N = number of patients with non-missing data

Table 2. Admission Diagnoses (*N*=71)

	n (%)
Psychiatric disorder[a]	14 (19.7%)
Fracture or trauma	7 (9.9%)
Renal failure/Disease	7 (9.9%)
Respiratory failure/Disease	7 (9.9%)
Cancer	4 (5.6%)
Gastrointestinal disorder	4 (5.6%)
Sepsis	4 (5.6%)
Stroke	4 (5.6%)
Dementia	2 (2.8%)
Other[b]	18 (25.3%)

[a]*Psychiatric disorder includes: depressive disorder, bipolar disorder, schizophrenia, schizoaffective disorder, mental retardation, dysthymic disorder, and delusions*
[b]*Other includes: syncope and collapse, adult physical abuse, joint pain, malformation of orthopedic device, alcohol complications, drug overdose, HIV/AIDS, hepatic failure/disease, metabolic disorder, seizures, and other general symptoms*
N = number of patients with medical records available

The number of cases where the physician was awaiting a court order is reflective of the fact that, during the study time period, a guardian was required to petition the court separately for a DNR order or removal of life-sustaining treatments. Since March 4, 2008, court-appointed guardians have been allowed to make decisions regarding consent or refusal of treatment, including DNR orders, without returning to court for a specific order.[12]

Withdrawal of Life-sustaining Treatment. There were three patients who died during hospitalization following withdrawal of treatment. In two of these patients' cases a court order obtained by the guardian authorized the withdrawal of treatment. In the third case, although a temporary guardian was requested, the family, who was out of the country, was able to consent to withdrawal of treatment over the phone with the use of an interpreter and the guardianship petition was withdrawn.

Two patients had a decision made by a court-appointed guardian to withdraw life-prolonging treatments and proceed to comfort care upon discharge to an extended care facility.

Table 3. Cause of Incapacitation (*N*=71)

	n (%)
Dementia	32 (45.1%)
Psychiatric disorder[a]	9 (12.7%)
Altered mental status	5 (7.0%)
Cognitive impairment	4 (5.6%)
Stroke	4 (5.6%)
Mental retardation	3 (4.2%)
Anoxic brain injury	3 (4.2%)
Traumatic brain injury	3 (4.2%)
ETOH abuse/withdrawal	3 (4.2%)
Delirium	3 (4.2%)
Sepsis	2 (2.8%)

[a]*Psychiatric Disorder includes: Psychiatric disorder, delusions, depression, and psychosis*
N = number of patients with medical record available

Table 4. Disposition at Admission and Discharge

Disposition at admission (*N*=71)	*n*	%
Living alone	33	46.5
Living with family	13	18.3
Homeless	12	16.9
Living with friend	6	8.5
Nursing home	4	5.6
Unknown	3	4.2
Disposition at discharge (*N*=71)	*n*	%
Extended care facility	60	84.5
Died	4	5.6
Psychiatric unit	3	4.2
Home	2	2.8
Veterans Administration hospital	2	2.8

N = number of patients with medical record available

Table 5. Code Status

	n (%)
Code status at admission (*N*=71)	
Full code	69 (97.2%)
Partial code	1 (1.4%)
DNR	1 (1.4%)
Full or partial code changed to DNR (*N*=70)	
No	53 (75.7%)
Yes	17 (24.3%)
Person making decision to change code to DNR (*N*=17)	
Palliative care	5 (29.4%)
Medical team	3 (17.6%)
Patient	3 (17.6%)
Family	3 (17.6%)
Unknown	2 (11.8%)
Court-appointed guardian	1 (5.9%)

N = number of patients with non-missing data; DNR = do not resuscitate

Invasive Procedures. Overall, 32 of 71 patients underwent a total of 81 documented invasive procedures for which documentation of consent could be located during data collection. Sixteen of these 81 procedures were authorized by the patient, 15 by family or friend, and 11 by a guardian (Table 6). Consent was not required for 39 of the procedures because of emergency conditions or medical necessity; 18 of these 39 procedures were for intubation with mechanical ventilation and seven were for a surgical procedure (Table 6).

Of the 81 documented invasive procedures, 62 were performed prior to temporary guardianship appointment. After appointment, temporary guardians provided consent for 11 of 13 procedures. Of the two patients who did not have guardian consent after appointment, one had a transfusion performed due to medical necessity because the physician was "unable to reach state guardian" and the other patient had an endoscopy and PEG tube performed with her mother's consent, despite guardianship appointment.

Guardianship

For 63 (88.7%) of 71 patients the reason for guardianship was for placement only, as reflected in the legal file (Table 7). Chart notes were reviewed for information regarding whether or not a family member was available at the time of the petition for guardianship. Forty-five (67.2%) of 71 patients had a family member available who was not appointed as temporary guardian. The most common documented reason an available family member did not serve as guardian was that the family member was unable or unwilling (Table 7). Fifty-two (73.2%) of 71 patients had a state guardian appointed as their permanent guardian, 22.5% had a family member or friend appointed, and 1.4% had a caseworker appointed as permanent guardian (Table 7).

The median time between patients' admission and the date of documented incapacitation was 1 day (range=0 to 17 days). The median time between documented incapacitation and guardianship request (resulting in appointment of a temporary guardian able to make decisions for the patient) was 14 days (range=2 to 90 days). The median time between guardianship request and appointment of permanent guardianship was 37 days (range=16 to 71 days).

Overall, 23 (32.4%) of 71 patients had a total of 36 instances of chart documentation indicating that a member of their medical team had some type of contact with the court-appointed guardian, one of which included documentation indicating that the patient had met the court-appointed guardian in person (Table 8). Social workers had the most documented contact with the court-appointed guardians, due mainly to discussions of placement (Table 8).

DISCUSSION

Our data reveal that many critical health care decisions were required for patients while they were awaiting guardianship and often the decision-making fell to physicians. Similar results were found by White et al. in two studies reviewing how decisions to withdraw life support were made for incapacitated patients without surrogates. The first study was conducted in a single ICU over a 7-month period and found that, for 49 incapacitated patients who remained incapacitated and without a surrogate decision-make during their entire ICU admission, physicians considered withdrawing life support or writing DNR orders for 18 patients (37%).

Decisions to withdraw life support were made mostly by the ICU physician (with the concurrence of another physician) or the ICU team. Decisions to write DNR orders were made mostly by the ICU physician and the medical team or the ICU physician with the concurrence another physician; less commonly, the DNR orders were written in conjunction with a hospital ethics committee or following petition for a court-appointed guardian.[15] In the other study by White et al., which was conducted in ICUs at seven medical centers over a two-year period, there were 37 incapacitated patients without surrogates for whom physicians considered limiting life support or would have done so if a surrogate had been available. In making life support decisions for these patients, ICU physicians consulted with other ICU team members (10 patients), another attending physician (15 patients), a hospital review committee (6 patients), or sought guidance from a court (one patient).[16]

Table 6. Decision-Makers for Invasive Procedures by Type of Procedure (*N*=81)

	Court-appointed guardian	Family or friend[a]	Consent not required[b]	Patient	Total
	n	*n*	*n*	*n*	*n*
Catheterization[c]	1	1	3	2	7
Diagnostic tests[d]	1	4	4	6	15
Dialysis	1	0	4	0	5
PEG tube	3	7	1	1	12
Surgery[e]	4	2	7	5	18
Transfusion	1	1	2	2	6
Ventilator	0	0	18	0	18
Total	11 (13.6%)	15 (18.5%)	39 (48.1%)	16 (19.8%)	81 (100%)

[a]*Family or friend includes: two daughters; one ex-mother in law who only had financial power of attorney, one friend, one mother, two nieces, six sisters, one girlfriend, and one wife*
[b]*Procedures were captured as 'consent not required' if they were performed due to emergency (e.g., mechanical ventilation initiated due to respiratory distress) or if a chart note indicated that the patient's condition would worsen without treatment and an appropriate surrogate could not be contacted*
[c]*Catheterization includes: venous catheterization, Hickman catheter, intercostal catheterization, and arterial catheterization*
[d]*Diagnostic includes: spinal tap, skin biopsy, MRI with conscious sedation, MRI with contrast, bronchoscopy, HIV testing, bronchial biopsy, biopsy of large intestine, upper GI, endoscopy, and lumbar puncture*
[e]*Surgery includes: exploratory laparotomy, cholecystectomy, vascular access, tracheostomy, pacemaker, thoracentesis, arteriovenostomy, skin closure, abdomen drainage, fracture reduction, paracentesis, hip replacement, sigmoidectomy, and pleurodesis injection*

A strong assumption exists that patients who are hospitalized and have no surrogate decision maker are friendless and alone[2]; however, most of the patients in our study had a family member available at the time that guardianship was requested who was unable or unwilling to act as guardian. Future research should explore the reasons why some family members are unable to serve as guardians. Some barriers, such as difficulty paying attorney or court fees, may be remediable. A few studies have been conducted in order to estimate the number of elderly patients in long-term care institutions who are at risk of being incapacitated and alone.[17,18] The limitation with this type of estimation is that it focuses on the elderly in long-term care institutions and does not account for the type of patients who live in the community and may have additional family resources, as was the case with many of the patients in our study.

Table 7. Guardianship (*N*=71)

Reason for temporary guardianship	*n*	%
Placement only	63	88.7
Hospice/Comfort care	4	5.6
Health care decisions and placement	2	2.8
Health care decisions only	1	1.4
Request DNR order	1	1.4
Family available	*n*	%*
Yes	45	67.2
No	22	32.8
Missing	4	
Reason family not temporary guardian	*n*	%*
Family unable/unwilling	34	50.7
Family not available	22	32.8
Family estranged	6	9.0
Family unacceptable	3	4.5
Patient refused family as guardian	2	3.0
Missing	4	
Relationship of permanent guardian	*n*	%
State	52	73.2
Extended family[a]	7	9.9
Friend	3	4.2
Parent	2	2.8
Child	2	2.8
Unknown	2	2.8
Spouse	1	1.4
Sibling	1	1.4
Caseworker	1	1.4

[a]*Extended family includes: Aunt, ex mother-in-law, granddaughter, granddaughter-in-law, and niece*
N = number of patients with medical record available; DNR = do not resuscitate
**Percentages based on number of patients with non-missing values*

Table 8. Documentation of Contact with Court-Appointed Guardians

	n	Person contacting/Method of contact
Discussion of change from aggressive to palliative care	5	
	1	Unknown/Phone
	1	Palliative care/Phone
	1	Social worker/Unknown
	1	Trauma/In person
	1	Palliative care/Unknown
Discussion of placement	19	
	9	Social worker/Phone
	3	Geriatrics consult service/ Phone
	1	Social worker/Unknown
	1	Social worker/In Person
	1	Social worker/Fax
	1	Certified nursing staff/ In Person[a]
	1	Geriatrics consult service/ Unknown
	1	Psychiatry/In person
	1	Unknown/Unknown[b]
Discussion of interventions requiring informed consent	11	
	8	Medicine/Phone
	1	Certified nursing staff/Phone
	1	Unknown/phone
	1	Social worker/In person
Discussion of removing life support	1	
	1	Palliative care/In person

[a]*This is only instance documented where patient was introduced to guardian*
[b]*Signature for release of information obtained; does not specify how.*
Findings of 'Contacted' or 'Spoke with' in the chart notes were interpreted as 'Phone' contact.
Categories are not mutually exclusive

Only 32.4% of patients had chart documentation indicating that a member of the medical team had some type of contact with the court-appointed guardian. Although lack of chart documentation alone is not conclusive, it suggests that guardians may have little contact with the medical team and with the patients for whom they serve as decision-makers. Given the expected increase in the elderly population and the number of patients with dementia, more comprehensive guardianship programs and standard state-level guidelines are needed to ensure that quality care is received by these patients.[19] Although a thorough discussion of guardianship reform is outside the scope of this paper, it should be noted that efforts are currently underway at national and state levels to improve state guardianship programs and judicial oversight of guardians.[19–22] As part of its own guardianship reform process the state of Indiana has implemented a statewide initiative to develop sustainable community-based adult guardianship services. The Indiana Adult Guardianship Services Project (IAGS) is sponsoring research to review guardianship demographics, statutes, ethics, standards, and regulations in Indiana and nationally to assist in building best practices for guardianship monitoring.[23]

This study has several limitations. The study was conducted as a retrospective chart review and all chart documentation may not have been accessible during data collection. We were only able to examine patients who had a request submitted for guardianship and not those who may have been incapacitated but did not have a request submitted. In addition, no contact was made with patients undergoing the guardianship process nor were there formal interviews with guardians. Thus, there is likely to be an information gap between what actually happened to patients and what was documented in the record. Finally, the study was conducted in a single, publicly funded hospital in a large city in the Midwest and the data may not be representative of other populations of patients, other hospitals, or other geographical regions and legal jurisdictions.

In conclusion, these findings draw attention to the fact that unbefriended adults may lack a surrogate decision maker when serious decisions must be made about their medical care. More research is necessary to: 1) identify patients who are at risk for not having family members or friends available to assist in health care decisions; 2) determine how the guardianship process can be improved to better serve this patient population; and 3) determine how communication between health care professionals and court-appointed guardians can be improved.

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