Legal and Ethical Risks of Unrepresented Patients

GEORGIA SOCIETY FOR HEALTHCARE RISK MANAGEMENT

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The views, opinions and positions expressed in this presentation do not necessarily reflect the views of our employers.

We have no conflicts of interest to disclose.

PHI is de-identified.

No legal advice intended and no attorney-client relationship created.
Introducing Us

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Introducing Our Patient

Mr. K is a 68 year old man who has lived at a local nursing home for 5 years after he suffered a stroke. He is bedbound, contracted, and has dysphagia and speech difficulties. He requires assistance with all ADLs, especially eating, but will eat when a staff member feeds him.

The nursing home transfers him to the hospital for possible lower extremity amputation. The nursing home then refuses to take him back without a DNR order in place. Clinically, he is not a candidate for amputation or for the DNR. He is unable to make decisions for himself and has no surrogate to make decisions for him.
"Unbefriended" or Unrepresented Patient

Patient who:

(1) does not have decisional capacity to give informed consent to treatment;

(2) has not executed an advance directive; and

(3) has no legally authorized surrogate, family/next of kin, or friend to make decisions

Often elderly, homeless, mentally ill, socially isolated
By the Numbers

2 studies in 2006 showed 16% of ICU patients lacked capacity and lacked a surrogate decision maker

5.5% of deaths in ICU were unbefriended patients

3% of nursing home residents

*These numbers are growing!*

What is Guardianship?

Guardianship...is a legal process, utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable.
Considering Guardianship?
A Roadmap for Hospital Clinicians and Staff

(1) What is the clinical decision to be made?
   (emergency, routine, major medical, end of life*)

(2) Does the patient lack capacity?

(3) Is a surrogate available?

(4) Has patient previously expressed his or her wishes?

(5) Choice of appropriate method to help patient

Emergency and Permanent Guardianship

Emergency (lasts for 60 days) vs. permanent

Emergency requires that the facts support the need for a guardian and the facts that establish an *immediate and substantial risk* of death or serious physical injury, illness, or disease.

Permanent requires that the facts support the need for a guardian and demonstrate how that adult *lacks sufficient capacity to make or communicate significant responsible decisions* concerning the management of his or her health or safety.
Process for Guardian/Conservator

**Petition**
- Petition filed with Probate Court of county where patient is hospitalized – petitioner is generally social worker, include affidavit from physician

**Evaluation**
- Court assigns a LCSW or MSW to evaluate the patient

**Hearing**
- Once evaluation received, Court assigns attorney for patient and sets hearing

**Evidence**
- "Clear and convincing"
Relationships

Do you know your county Probate Court judge?

Do you know your area supervisor for the Department of Human Services?
My Patient Needs a Guardian!

DR: MY PATIENT NEEDS A GUARDIAN!

ME: NO HE DOESN'T!
Right Patient, Right Procedure, Right Approach

Interdisciplinary focus on the needs of the patient – determine clinical decisions first

Decision-specific capacity assessments

Diligent searches for surrogates

Ethical considerations

Educate staff
Unrepresented Patients: the bedside issues
Making Medical Treatment Decisions for Unrepresented Patients in the ICU


This official policy statement was approved by the American Thoracic Society February 2020 and the American Geriatrics Society January 2020
5 Ethical Goals in Caring for Unrepresented Patients

- Protect highly vulnerable patients
- Demonstrate respect for persons
- Provide appropriate medical care
- Safeguard against unacceptable discrimination
- Avoid undue influence of conflicts of interest

Unrepresented Patients are Highly Vulnerable

Cannot advocate for themselves

Lack friends or family to advocate on their behalf

Dependent on the institution and its clinicians
It is difficult to demonstrate Respect for Persons

Requires an acknowledgement of each person’s worth and dignity

Learning about the individuality, values, goals, culture, and preferences of a patient

The unrepresented are at risk for not having their wishes known or followed
Unrepresented Patients Might Not Receive Appropriate Care

Evidence shows that the absence of a decision-maker leaves patients vulnerable to

- Overtreatment
- Undertreatment
- Treatment inconsistent with the patient’s preferences and values
Ethical Concerns Arising in Caring for Unrepresented Patients

No one to engage in Shared Decision-Making with the clinical team

3 Possible Approaches to Providing Care

1. Erring on the side of prolonging life, clinicians might **treat** the patient **without consent**.
   - administer prolonged life-sustaining treatment
     - despite limited prospects of benefit
     - despite burdens on the patient
     - despite evidence of the patient’s wishes to avoid such treatment

2. Clinicians might **withhold or withdraw** treatment because they unilaterally deem it to be potentially inappropriate.

3. Clinicians may **delay** treatment until the patient regains capacity or a court-appointed surrogate decision-maker is identified.
The absence of an authorized surrogate often results in “maximum medical intervention, whether or not a medical ‘full court press’ is clinically and ethically warranted”

1. Fear of not providing appropriate treatment
2. Fear of liability for failure to treat
3. Fear of regulatory sanctions
4. Economic incentives to treat
5. General interventionist philosophy of medicine
Effects on Bedside Staff

**Moral distress:** the emotional state that arises from a situation when staff feel that the ethically correct action to take is different from what they are tasked with doing.
Unrepresented Patients May Face Unacceptable Discrimination

Treatment decisions may be influenced by medically irrelevant characteristics
  ◦ E.g. Race, gender, social worth, undocumented status

Implicit biases may go unchecked

Unrepresented patients are often members of marginalized groups subject to discrimination
  ◦ E.g. Homeless, mental illness, substance use
Unrepresented Patients are at Risk of Undue Influence in Decision-Making

Financial interests of provider / institution
  ◦ Fee-for-service model → overtreatment
  ◦ Capitated model → undertreatment

Pressure for scarce ICU beds
Clinical Decision-Making for Patients Who Lack a Representative
General methods of surrogate decision making

Surrogate decision makers should use substitutive judgment according to their knowledge of the patient’s preferences, or when there is no such knowledge, a surrogate should make decisions that are thought to be in the patient’s best interest. (AMA Code of Ethics 2.1.2)

- Stated preferences/goals of care
- Past decisions about healthcare
- Beliefs, generally, about life, death, suffering, etc.

Substitutive Judgment

- Unknown preferences about healthcare specifically, but general consideration of what would be best for the patient
- Have care and concern, but lack specific knowledge

Best Interests
The Challenge

Healthcare decisions always focus on a patient’s own preferences

When those preferences are unknown, another person who knows the patient acts as a surrogate decision-maker and is responsible for acting in “good faith to consent to surgical or medical treatment or procedures which the patient would have wanted had the patient understood the circumstances under which such treatment or procedures are provided” – O.C.G.A. § 31-9-2(b)

But if a patient lacks a representative who knows them, how should the clinical team make treatment decisions?
Clinical decision needed (e.g. blood transfusion)

Is the procedure “emergent” per Georgia Law? & Is there no authorized person to consent who is readily available?  

**Yes:** Consent is implied, proceed with necessary treatment

**No:** Consent is necessary, wait until patient regains capacity, a surrogate is located, or need becomes emergent
What constitutes an “Emergency?”

OCGA § 31-9-3. Emergencies

(a) As used in this Code section, the term "emergency" means a situation wherein

◦ (1) according to competent medical judgment, the proposed surgical or medical treatment or procedures are reasonably necessary and

◦ (2) a person authorized to consent under Code Section 31-9-2 is not readily available and any delay in treatment could reasonably be expected to jeopardize the life or health of the person affected or could reasonably result in disfigurement or impaired faculties.

(b) In addition to any instances in which a consent is excused or implied at law, a consent to surgical or medical treatment or procedures suggested, recommended, prescribed, or directed by a duly licensed physician will be implied where an emergency exists.
What is “readily available?”

No specific definition in the statute, but in practice it generally means no person is reachable and any further delay would jeopardize the patient’s health or wellbeing.

If time allows, would conduct a diligent search for a surrogate, such as:

- Chart review for names
- Requesting info from other providers
- Internet search/Address look-up
- Contacting authorities to check address
- Use legal/private investigative services
Ethical Risks/Benefits of Emergency Consent

Benefits
- Allows provision of necessary treatment without further delay
- Broad enough to cover a multitude of necessary interventions
- Grants legal protection for clinicians who are trying to do the best thing
- Represents the average person’s preference for emergency situations

Risks
- Broad language may allow for abuse of discretion, proceeding with treatment more out of convenience rather than necessity
- Treating team, and hospital at large, has inherent conflicts of interest
- Interpretations and application varies from hospital to hospital and even from clinician to clinician
Other potential means of decision-making

Seeking consent from a guardian
- Besides typical guardianship, may also be potential for a temporary medical consent guardian

Decision by committee
- e.g. Ethics Committee, designated multidisciplinary group, smaller social work/patient advocate group, etc.

Inference per advance directive/advance care planning
- If an Adv. Dir. Is clearly applicable it should be followed, but in other cases it doesn’t directly apply but an inference can be made about preferences generally
Figure 1. Photograph of the Patient’s Tattoo Entered into the Medical Record to Document His Permanently Inactive End-of-Life Wishes.

This patient’s presumed signature has been redacted.
History

- 1960
  - Surgeons at Johns Hopkins reported a technique for closed chest massage combined with artificial respiration
  - Designed for transient and easily reversible conditions in otherwise healthy individuals (specifically patients suffering anesthesia-induced cardiac arrest)
  - “Anyone, anywhere, can now initiate cardiac resuscitative procedures. All that is needed are two hands.”

History

Mid 1960s
- The American Heart Association’s CPR Committee started
- The Heart Association formally endorsed CPR.
- 30 national organizations endorse CPR
- CPR essentially becomes the rule and the not the exception

Late 1960s
- Articles are published describing the suffering that patients experience from repeated resuscitations that only prolong dying
History

- Obligation is created to perform CPR on all patients, even when no it is of no clinical benefit
- Covert processes develop to avoid performing CPR
  - Don't call the code
  - “Slow codes”
  - “Show codes”
  - “Hollywood codes”
  - Purple dots on medical records
  - Penciled in for easy erasure
History

1974
- American Heart Association is first professional organization to propose that decisions not to resuscitate be formally documented

1976
- First hospital policies on orders not to resuscitate were published
History

Mid 1980s

◦ President’s Bioethics Commission
  ◦ Patients are presumed to want CPR
  ◦ When cardiac arrest is likely, a patient (or a surrogate) should usually be informed and offered the chance specifically to decide for or against resuscitation.

◦ DNR orders began as part of the patients’ rights to autonomy in the face of paternalistic doctors

◦ DNR is the only order that requires patient consent to prevent a medical procedure from being performed
Outcomes data

Retrospective study of 14,720 resuscitation attempts in adults from 2000-02: **17% survived to discharge**


Review of 433, 985 patients who underwent in hospital CPR: **18.3% survived to discharge**

Patient perception

• In 60 occurrences of CPR in 97 TV episodes (ER, Chicago Hope, Rescue 911)
  • 75% of the patients survived the immediate arrest
  • 67% appeared to have survived to hospital discharge


• Another study showed patients predicted their post-arrest survival to be 60.4% when it truly averaged 17%

### Troublesome data

#### Resident who wrote the orders

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Withhold</th>
<th>Apply</th>
<th>Undecided</th>
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<tbody>
<tr>
<td>CPR</td>
<td>100%</td>
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<td>0</td>
</tr>
<tr>
<td>Cardiac pacemaker</td>
<td>96%</td>
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<tr>
<td>Nursing care</td>
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### Cross-cover resident interpreting order

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Troublesome data...

Prospective survey of attending, resident, and intern physicians who had written a DNR order for 93 patients in their care

Once the DNR order is placed

- 42% would “probably” or “definitely” transfer pt out of the ICU
- 91% would “probably” or “definitely” withhold ICU transfer

Troublesome data...

- In a case based study, physicians agreed or strongly agreed to initiate fewer interventions when a DNR order was present versus absent
  - Transfer to an ICU
  - Intubation
  - Blood cultures
  - Central line placement
  - Blood transfusion

Troublesome data...

A recent study found that patients with DNR orders were less likely to have heart failure measures performed than patients without DNR orders

- LV function assessment (31% vs 43%)
- ARB treatment (49% vs 57%)
- Anticoagulation (65% vs 78%)
- Nonpharmacologic strategies (87% vs 92%)

Nurses too

In a survey study, 47% of nurses failed to distinguish a DNR from other end of life decisions.

- 72% felt a DNR should not receive aggressive interventions
- 65% felt that a patient with a DNR designation should not be admitted to an ICU.

Nurses too...

Hennenman, et al. studied the effect of DNR orders on the nursing care of critically ill patients.

- Nurses were significantly less likely to perform physiologic monitoring modalities and interventions on DNR patients
- Nurses reported a DNR “might” be misinterpreted to mean more than no CPR.

Some clarity?

A DNR order is an order not to attempt cardiopulmonary resuscitation in a patient who has suffered cardiopulmonary arrest.
Cardiopulmonary Resuscitation

- Set of techniques designed to restore circulation and respiration in the event of acute cardiac or cardiopulmonary arrest

- Most common causes
  - Cardiac arrhythmia
  - Acute respiratory insufficiency
  - Hypotension

- CPR is to be performed on any patient without having a written order
  - Need to have an order for omitting CPR, i.e., DNR
  - Very unique
DNR vs. DNI

One should not confuse a DNAR with a DNI

DNI is an order for “Do-not-intubate”

- It should be noted that effective CPR does require endotracheal intubation in most cases
- Therefore, patients who request a DNI order but wish to be resuscitated should be advised of the potential inconsistencies of such a request
Application in non-arrest settings

DNR order applies only in arrest settings

The problem is that continuum from pre-arrest to arrest isn’t always clear

Pre-arrest situations may present the need to manage dysrhythmias, ventilatory insufficiency, ineffective gas exchange, and respiratory distress
Some real problems

The expansion of DNR beyond its scope

Varied interpretations of DNR by physicians, nurses, patients, families

So, when a patient or surrogate says they don't want a DNR order because they think their loved one won't get treatment or care...are they right?
GA Hierarchy of Authorized Surrogate Decision-Makers

**MOST MEDICAL DECISIONS**
1. Health Care Power of Attorney/Health Care Agent
2. Spouse
3. Guardian*
4. Adult Children
5. Parents
6. Adult Siblings
7. Grandparent
8. Grandchild
9. Niece, Nephew, Aunt, Uncle (of the first degree)
10. Friend

**DNR ORDERS**
1. Health Care Power of Attorney/Health Care Agent
2. Spouse
3. Guardian
4. Adult Children
5. Parents
6. Adult Siblings
7. Ethics Consultation Service (Ethics Committee)
No surrogate

Ethics Consultation Service/Committee

- Two attendings document
  - Lack of Capacity
  - Lack of Authorized decision maker
  - DNR Candidacy Criteria

- Ethics Consultation service required for code status change
DNR Candidacy

- 2 Attendings document that patient
  - Has a medical condition which can reasonably be expected to result in the imminent death of the patient
  - OR
  - Is in a noncognitive state with no reasonable possibility of regaining cognitive functions;
  - OR
  - Is a person for whom cardiopulmonary resuscitation would be medically futile in that such resuscitation will likely be unsuccessful in restoring cardiac and respiratory function or will only restore cardiac and respiratory function for a brief period of time so that the patient will likely experience repeated need for cardiopulmonary resuscitation over a short period of time or that such resuscitation would be otherwise medically futile.
Back to Mr. K

Clinical Decisions
- Should he have an amputation
- Was he a candidate for DNR
- Was he a candidate for hospice

He lacked capacity

No surrogate located

No wishes previously expressed

Concerns regarding nursing home's treatment of him (vulnerable patient)

Emergency Guardianship
End of Presentation

ANY QUESTIONS?